Study on cross-border health services: enhancing information provision to patients

Annexes – Final Report

Written by the consortium of Ecorys, KU Leuven and GfK Belgium.

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Annexes – Final Report

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Preface

This document includes all annexes of the study on cross-border health services: enhancing information provision to patients.

The annexes outline the guiding principles and indicators (Annex A), main trends based on the online survey to NCPs (Annex B), and the overarching research protocol (Annex C). Furthermore, annexes specific to each of the WPs are detailed, including for the website analysis in WP2 (Annex D), for the pseudo-patient investigation in WP3 (Annex E-H), and for the analysis of other information centres (Annex I) and the online patient survey (Annex J) in WP4. Then, a list of the NCPs and their contact information is presented (Annex K). The final Annex includes a short note on the proceedings of the workshop on 8 March 2018 (Annex L).

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ANNEX A – GUIDING PRINCIPLES AND INDICATORS

This Annex includes:

1. *Nine General Guiding Principles*
2. *Specific technical Guidelines – up to five key Guidelines per Guiding Principles whilst the remainder represent voluntary good practices based on review of evidence*
3. *Voluntary set of Indicators - intended for self-assessment and monitoring*

Purpose:

The purpose of the "Guiding Principles for Cross-border Healthcare NCPs" is to set out key principles for good NCP services, in line with NCPs' obligations under Directive 2011/24/EU[1]. The Guiding Principles are designed to assist NCPs in their daily public task of providing clear and accurate information on the main aspects of cross-border healthcare. The principles aim to contribute to a NCP practice that is (1) more uniform, (2) of high quality, and (3) always patient-oriented.

In this light, the **Guiding Principles** cover the following main areas:

1. Accessibility and availability of the NCP service
2. Compatibility of information provision with Directive 2011/24/EU
3. Cooperation between NCPs and with other actors

Methodology:

The **Guiding Principles** are developed from the existing legal obligations and standards that rest on NCPs under Directive 2011/24/EU, as well as from the good practices identified in a recent study on enhancing information provision to patients in cross-border health services[2] and previous studies[3]. Besides, to ensure patient centeredness, recommendations by the European Patients' Forum (EPF) are taken into account.[4] The Guiding Principles were discussed at the NCP Workshop of 8 March 2018 and following further consultations, agreed with the consent of all cross-border healthcare NCPs.

The Guiding Principles provide the underlying framework for the more technical **NCP Guidelines**, that are each time listed under the principle concerned. These guidelines are likewise agreed by all NCPs. All guidelines aim to leave room for the existing organisational differences between NCPs.

To monitor the implementation of the guidelines, a voluntary set of **indicators** was created (see Part 2 of the document), following the RACER methodology. Accordingly, indicators that are Relevant, Accepted, Credible, Easy to monitor and Robust against manipulation are established. These indicators are intended for voluntary self-assessment and monitoring in light of compliance with the Guiding Principles and Guidelines.

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[1] Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare, *OJ* L 088, 4 April 2011, pp. 45-65.

[2] *"Study on cross-border health services: enhancing information provision to patients", on-going*.

[3] European Commission, Member State data on cross-border healthcare following Directive 2011/24/EU, 2015, p. 37 ; G. Zucca, A. De Negri, A. Berény, A. Kaszap, K.A. Stroetmann, P. Varnai, Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, p. 179; G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017, p. 101; ANEC, Cross-border healthcare. Accessing medical treatment in other EU countries: Consumer attitudes and experiences, 2018, p. 55.

[4] See amongst others: Summary Report: main conclusions and recommendations arising from EPF's series of Regional Conferences 2013-14; EPF, Recommendations for National Contact Points: arising from the EPF series of Regional Conferences 2013-14, 2015, p.7; Directive on Patients' Rights in Cross-border Healthcare: EPF Position Statement, 2016, pp. 22.

Besides the agreed Guiding Principles and Part 2 of the document, an additional set of indicators and guidelines that did not find common approval is provided in a separate document for further consideration, if so wished.

Schematic overview:

1. Nine General **Guiding Principles**
2. Specific technical **Guidelines –** up to five key Guidelines per Guiding Principle
3. Voluntary set of **Indicators** - intended for self-assessment and monitoring

The Guiding Principles

The Guiding Principles for Cross-border Healthcare NCPs are organised into three main strands, reflecting the major categories of NCP requirements according to the legal standards imposed by Directive 2011/24/EU:

- NCP service
- Information provision according to Directive 2011/24/EU
- Cooperation and information exchange

Each strand contents a number of Guiding Principles, describing the main features of good NCP service provision. In their turn, the principles provide the underlying framework for the more technical corresponding NCP Guidelines. In part 2 of this document, these specific guidelines are translated into voluntary thematic indicators, making it possible to monitor the implementation of the Guiding Principles in practice.

The Guiding Principles for Cross-border Healthcare NCPs:

NCP service

1. Principle of Visibility
2. Principle of Accessibility
3. Principle of Transparency
4. Principle of Inclusion

Information provision according to the Directive

5. Principle of Duality
6. Principle of Information to outgoing patients in accordance with the Directive
7. Principle of Information to incoming patients in accordance with the Directive

Cooperation & information exchange

8. Principle of information to healthcare providers
9. Principle of Cooperation

This framework includes the nine Guiding Principles for good NCP practice. Principle 1 to 4 are the overarching central principles that should be applied in every feature of the NCP service. Principle 5 to 7 are intended specifically for safeguarding information provision in accordance with the information requirements of Directive 2011/24/EU, making a distinction between information provision to outgoing patients and information provision to incoming patients. Principle 8 prescribes the duty of good information provision to healthcare providers. Finally, principle 9 concerns cooperation and information exchange between NCPs and with other actors.

Below, each principle is explained through a short commentary. The associated specific guidelines are listed under the Guiding Principle concerned. When applicable, the legal standards supporting the principles are outlined in separate boxes. An additional set of indicators and guidelines that did not find common approval is provided in a separate document. This constitutes source material for further consideration.

General Guiding Principles for good NCP service

Principle 1: Visibility

To comply with their duty of enhancing visibility of patients' rights under Directive 2011/24/EU, NCPs make sure their information reaches the general public. Accordingly, NCPs are visible, present and public.

1. *NCPs are highly visible and easy to find and recognise as appropriate.*
2. *When this is within the responsibility of the NCP and subject to available resources, NCPs try to be engaged in campaigns indented to inform the general public of their existence.*
3. *To map the awareness of the existence of NCPs, and as far as possible NCPs collect data on the number of patients making use of the NCP service.*

Legal standards:

- Recital 48: "Appropriate information on all essential aspects of cross- border healthcare is necessary in order to enable patients to exercise their rights on cross-border healthcare in practice. For cross-border healthcare, one of the mechanisms for providing such information is to establish national contact points within each Member State."
- Art. 6(1): "Each Member State shall designate one or more national contact points for cross-border healthcare and communicate their names and contact details to the Commission. The Commission and the Member States shall make this information publicly available. […]"
- Art. 6(5): "The information […] shall be easily accessible and shall be made available by electronic means and in formats accessible to people with disabilities, as appropriate."

Principle 2: Accessibility

The NCP service is easily accessible, via multiple channels and to all patients, bearing in mind special patients' information needs.

1. *NCPs have an accessible website that is informative and contains clear, structured and understandable information.*
2. *Subject to available resources and as appropriate, NCPs are accessible for direct and barrier-free personal patient advice, e.g. via email, postal service, online contact forms, telephone, or in person.*
3. *Depending on the available resources, NCPs try to provide information besides the national official language(s), in foreign languages, at least English, making the service also accessible for incoming patients.*

Legal standards:

- Art. 6(3): "In order to enable patients to make use of their rights in relation to cross-border healthcare, national contact points in the Member State of treatment shall provide them with information concerning healthcare providers, including, on request, information on a specific provider's right to provide services or any restrictions on its practice, information referred to in Article 4(2)(a), as well as information on patients' rights, complaints procedures and mechanisms for seeking remedies, according to the legislation of that Member State, as well as the legal and administrative options available to settle disputes, including in the event of harm arising from cross-border healthcare."
- Art. 6(5): "The information […] shall be easily accessible and shall be made available by electronic means and in formats accessible to people with disabilities, as appropriate."
- Recital 48: "Information that has to be provided compulsorily to patients should be specified."
- Recital 49: "The national contact points should have appropriate facilities to provide information on the main aspects of cross-border healthcare."
- Recital 48: "Information should be provided by national contact points to patients in any of the official languages of the Member State in which the contact points are situated. Information may be provided in any other language."
- Recital 20: "In order to help patients to make an informed choice when they seek to receive healthcare in another Member State, Member States of treatment should ensure that patients from other Member States receive on request the relevant information […]"

Principle 3: Transparency

NCPs operate through transparent procedures and clear timelines.

1. *NCPs provide information about their organisation and service. They try to answer all inquiries as soon as possible subject to available resources and taking into consideration domestic law.*
2. *Taking national work processes under consideration, NCPs try to collect data about their working process, aiming to monitor their efficiency and performance.*
3. *When this is within the NCP's competence, NCPs are transparent on the patients' rights and entitlements in accessing healthcare abroad.*
4. *When this is within the NCP's competence, NCPs provide patients with accessible and transparent procedures regarding accessing healthcare abroad.*
5. *When this is within the NCP's competence, NCPs provide outgoing patients with transparent procedures and clear time lines to appeal any decision regarding accessing healthcare abroad.*

Legal standards:

- Art. 7(9):"The Member State of affiliation may limit the application of the rules on reimbursement for cross-border healthcare based on overriding reasons of general interest, such as planning requirements relating to the aim of ensuring sufficient and permanent access to a balanced range of high-quality treatment in the Member State concerned or to the wish to control costs and avoid, as far as possible, any waste of financial, technical and human resources."
- Art. 7(11): "The decision to limit the application of this Article pursuant to paragraph 9 shall be restricted to what is necessary and proportionate, and may not constitute a means of arbitrary discrimination or an unjustified obstacle to the free movement of goods, persons or services. Member States shall notify the Commission of any decisions to limit reimbursement on the grounds stated in paragraph 9."
- Art. 8(1): "The Member State of affiliation may provide for a system of prior authorisation for reimbursement of costs of cross- border healthcare, in accordance with this Article and Article 9. The system of prior authorisation, including the criteria and the application of those criteria, and individual decisions of refusal to grant prior authorisation, shall be restricted to what is necessary and proportionate, and may not constitute a means of arbitrary discrimination is necessary and proportionate to the objective to be achieved, and may not constitute a means of arbitrary discrimination or an unjustified obstacle to the free movement of patients."
- Art. 8(7): "The Member State of affiliation shall make publicly available which healthcare is subject to prior authorisation for the purposes of this Directive, as well as all relevant information on the system of prior authorisation."
- Art. 9(1-4): "The Member State of affiliation shall ensure that administrative procedures regarding the use of cross-border healthcare and reimbursement of costs of healthcare incurred in another Member State are based on objective, non-discriminatory criteria which are necessary and proportionate to the objective to be achieved.
- Any administrative procedure of the kind referred to in paragraph 1 shall be easily accessible and information relating to such a procedure shall be made publicly available at the appropriate level. Such a procedure shall be capable of ensuring that requests are dealt with objectively and impartially.
- Member States shall set out reasonable periods of time within which requests for cross-border healthcare must be dealt with and make them public in advance. […] Member States shall ensure that individual decisions regarding the use of cross-border healthcare and reimbursement of costs of healthcare incurred in another Member State are properly reasoned and subject, on a case-by-case basis, to review and are capable of being challenged in judicial proceedings, which include provision for interim measures."
- Art. 9(5): "This Directive is without prejudice to Member States' right to offer patients a voluntary system of prior notification whereby, in return for such notification, the patient receives a written confirmation of the amount to be reimbursed on the basis of an estimate. This estimate shall take into account the patient's clinical case, specifying the medical procedures likely to apply.

- Member States may choose to apply the mechanisms of financial compensation between the competent institutions as provided for by Regulation (EC) No 883/2004. Where a Member State of affiliation does not apply such mechanisms, it shall ensure that patients receive reimbursement without undue delay."
- Art. 20(2): "[…]The Member States shall provide the Commission with assistance and all available information for carrying out the assessment and preparing the reports."
- Recital 47: "Procedures regarding cross-border healthcare established by the Member States should give patients guarantees of objectivity, non-discrimination and transparency, in such a way as to ensure that decisions by national authorities are made in a timely manner and with due care and regard for both those overall principles and the individual circumstances of each case. This should also apply to the actual reimbursement of costs of healthcare incurred in another Member State after the patient has received treatment. It is appropriate that, under normal circumstances, patients be entitled to receive decisions regarding cross-border healthcare within a reasonable period of time. However, that period should be shortened where warranted by the urgency of the treatment in question."
- Recital 49: "National contact points should be established in an efficient and transparent way […]."

Principle 4: Inclusion

NCPs recognise and support the right of people with disabilities to equal access of healthcare in other EU/EEA countries under Directive 2011/24/EU.

1. *Subject to available resources, NCPs offer informed assistance to help patients with disabilities to understand and exercise their rights in accessing healthcare abroad. Information provision by NCPs is provided in formats that are easily accessible for patients with disabilities, as appropriate.*
2. *Subject to available resources, NCPs arrange for education and training of its staff on the specific needs of patients with disabilities, taking into consideration different types of disabilities.*
3. *All NCPs provide information to incoming patients on the accessibility of hospitals for persons with disabilities.*

Legal standards:

- Art. 6(5): “The information […] shall be easily accessible and shall be made available by electronic means and in formats accessible to people with disabilities, as appropriate.”

Guiding Principles for information provision according to Directive 2011/24/EU

Principle 5: Duality

NCPs fulfil a dual function as gateway to cross-border health services for both outgoing patients going abroad for treatment as for incoming patients traveling from abroad to receive treatment in the Member State where the NCP is located.

1. *In accordance with Directive 2011/24/EU, NCPs make a clear distinction between information provision to outgoing patients and information provision to incoming patients.*
2. *NCPs facilitate the contact of patients with NCPs of other Member States.*

Legal standards:

- Art. 6(3): "In order to enable patients to make use of their rights in relation to cross-border healthcare, national contact points in the Member State of treatment shall provide them with information concerning healthcare providers, […]."
- Art. 6(4): "National contact points in the Member State of affiliation shall provide patients and health professionals with the information […]."
- Art. 6(2): "National contact points shall provide patients on request with contact details of national contact points in other Member States."

Principle 6: Information to outgoing patients in accordance with Directive 2011/24/EU

In their role as NCP of the Member State of affiliation, NCPs provide all mandatory information under Directive 2011/24/EU. Besides, NCPs provide patients with practical information needed to ensure safe and high-quality cross-border healthcare.

1. *NCPs provide outgoing patients with information on patients' rights and entitlements in cross-border health services.*
2. *NCPs inform patients on the existence of two parallel routes if appropriate. They make a clear distinction on the use of the Social Security Regulations versus Directive 2011/24/EU, and the respective consequences for patients.*
3. *NCPs provide outgoing patients with information on the financial aspect of cross-border healthcare. They provide information on the terms and conditions for receiving reimbursement of costs and on what extra costs need to be covered by the patient him-/herself. This includes information on the procedures and competent authorities for accessing and determining those entitlements, as well as on the procedures for appeal and redress if patients consider that their rights have not been respected.*
4. *NCPs inform patients on the importance of gathering sufficient information about the treatment and healthcare provider abroad. They refer the patient for this information to the NCP of the Member State of treatment.*
5. *NCPs inform patients on the importance of the transfer of medical records. Patients should be cautioned on the risk of receiving treatment without such transfer.*

Legal standards:

- Art. 5(b): "[…] with information on their rights and entitlements in that Member State relating to receiving cross-border healthcare, in particular as regards the terms and conditions for reimbursement of costs in accordance with Article 7(6) and procedures for accessing and determining those entitlements and for appeal and redress if patients consider that their rights have not been respected, in accordance with Article 9. In information about cross- border healthcare, a clear distinction shall be made between the rights which patients have by virtue of this Directive and rights arising from Regulation (EC) No 883/2004."
- Art. 6(4): "National contact points in the Member State of affiliation shall provide patients and health professionals with the information referred to in Article 5(b)."
- Art. 8(7): "The Member State of affiliation shall make publicly available which healthcare is subject to prior authorisation for the purposes of this Directive, as well as all relevant information on the system of prior authorisation."
- Recital 31: "Where the patient is entitled to cross-border healthcare under both this Directive and Regulation (EC) No 883/2004, and the application of that Regulation is more advantageous to the patient, the patient's attention should be drawn to this by the Member State of affiliation."

Principle 7: Information to incoming patients in accordance with Directive 2011/24/EU

In their role as NCP of the Member State of treatment, NCPs provide all mandatory information under Directive 2011/24/EU.

1. *NCPs inform patients on the importance of gathering sufficient information on needed application forms and reimbursement. They refer the patient for this information to the NCP of the Member State of affiliation.*
2. *To make patients acquainted with healthcare in their country, NCPs provide incoming patients with general information on their healthcare system, as it pertains to the individual patient as appropriate.*
3. *To ensure safe cross-border treatment, NCPs provide incoming patients with general information on quality and safety standards enforced in their MS, as well as information on which healthcare providers are subjected to these standards.*
4. *NCPs provide incoming patients with accurate information on healthcare providers and healthcare facilities established in their MS in so far as possible. NCPs provide general information on supervision and assessment of healthcare providers. Besides, NCPs inform patients on a specific provider's right to provide services or any restrictions on this practice, e.g. suspension, as available via the IMI or the NCP network.*
5. *NCPs inform incoming patients on patients' rights, complaints procedures and mechanisms for seeking remedies. Besides, NCPs provide information on the legal and administrative options available to settle disputes, including in case of harm arising from the event of cross-border healthcare, bearing in mind that this will mainly relate to referring the patient to the relevant responsible body.*

Legal standards:

- Art. 4(2)(a): "Patients receive […], upon request, relevant information on the standards and guidelines referred to in paragraph 1(b) of this Article, including provisions on supervision and assessment of healthcare providers, information on which healthcare providers are subject to these standards and guidelines and information on the accessibility of hospitals for persons with disabilities."
- Art. 6(3): "In order to enable patients to make use of their rights in relation to cross-border healthcare, national contact points in the Member State of treatment shall provide them with information concerning healthcare providers, including, on request, information on a specific provider's right to provide services or any restrictions on its practice, information referred to in Article 4(2)(a), as well as information on patients' rights, complaints procedures and mechanisms for seeking remedies, according to the legislation of that Member State, as well as the legal and administrative options available to settle disputes, including in the event of harm arising from cross-border healthcare."

Principle 8: Information provision to healthcare providers

NCPs provide healthcare providers with information on cross-border health services.

1. *NCPs provide healthcare providers with information on patients' rights and entitlements in cross-border health services under Directive 2011/24/EU and the Social Security Regulations.*
2. *NCPs provide healthcare providers with information on their duty to provide information towards their patients according to Directive 2011/24/EU.*

Legal standards:

- Art. 4(2)(b): "Healthcare providers provide relevant information to help individual patients to make an informed choice, including on treatment options, on the availability, quality and safety of the healthcare they provide in the Member State of treatment and that they also provide clear invoices and clear information on prices, as well as on their authorisation or registration status, their insurance cover or other means of personal or collective protection with regard to professional liability."
- Art. 6(4): "National contact points in the Member State of affiliation shall provide patients and health professionals with the information referred to in Article 5(b)."
- Art. 5(b): "[…] with information on their rights and entitlements in that Member State relating to receiving cross-border healthcare, in particular as regards the terms and conditions for reimbursement of costs in accordance with Article 7(6) and procedures for accessing and determining those entitlements and for appeal and redress if patients consider that their rights have not been respected, in accordance with Article 9. In information about cross- border healthcare, a clear distinction shall be made between the rights which patients have by virtue of this Directive and rights arising from Regulation (EC) No 883/2004."

Guiding Principles for good cooperation and information exchange:

Principle 9: Cooperation amongst NCPs

To facilitate the exchange of information, NCPs render mutual assistance and cooperate closely with each other.

1. *NCPs should maintain partnerships amongst each other, making it easy to exchange information and build on each other's best practices.*
2. *NCPs should assist each other in answering patients' inquiries and finding solutions that are the best fit for the specific patient's needs during the entire process of treatment abroad.*
3. *NCPs should consult with other stakeholders, such as healthcare providers, national health insurance funds, patient organisations,…*

Legal standards:

- Art. 6(2): "National contact points shall facilitate the exchange of information […] and shall cooperate closely with each other and with the Commission."
- Art. 6(1): "[…] national contact points consult with patient organisations, healthcare providers and healthcare insurers."
- Art. 10(1): "Member States shall render such mutual assistance as is necessary for the implementation of this Directive, including cooperation on standards and guidelines on quality and safety and the exchange of information, especially between their national contact points in accordance with Article 6, including on provisions on supervision and mutual assistance to clarify the content of invoices".

Voluntary Indicators for the Guiding Principles for Cross-border Healthcare National Contact Points (NCPs)

Principle 1: Visibility

1) NCPs are highly visible and easy to find and recognise as appropriate.

   Indicators:
   - NCPs conduct an everyday informative function
   - NCP website (independent website or at least dedicated web pages)
   - Clear statement of the NCP function and provision of contact details on the NCP website

2) When this is within the responsibility of the NCP and subject to available resources, NCPs try to be engaged in campaigns indented to inform the general public of their existence.

   Indicators:
   - Participation in conferences or events of patient organisations, healthcare providers or other stakeholders

3) To map the awareness of the existence of NCPs, and as far as possible NCPs collect data on the number of patients making use of the NCP service.

   Indicators:
   - Information requests estimates
   - Website traffic estimates

Principle 2: Accessibility

1) NCPs have an accessible website that is informative and contains clear, structured and understandable information.

   Indicators:
   - Structured format, e.g.:
     - Structured information (headings, sub-headings, paragraphs,…)
     - Internal search engine
     - Sitemap or content tree
   - Clear and understandable information, e.g.:
     - FAQs
     - Glossary
     - Visual tools (e.g. infographics, videos,..)
     - Guides and checklists
   - Reviewing of the NCP website on a regular basis with a minimum standard of once a year (this includes reviewing of contact details, checking factual accuracy, making improvements based on patients' feedback,..)

2) Subject to available resources and as appropriate, NCPs are accessible for direct and barrier-free personal patient advice, e.g. via email, postal service, online contact forms, telephone, or in person.

   Indicators:
   - Multiple contact channels, e.g.:
     - Web contact form
   - Avoidance of standard responses, e.g.:
     - Avoidance of Interactive Voice Response (IVR; automated telephony system); when IVR is inevitable: clear routing of callers with questions on cross-border treatment
     - Avoidance of standard email responses

3) Depending on the available resources, NCPs try to provide information besides the national official language(s), in foreign languages, at least English, making the service also accessible for incoming patients.

   Indicators:
   - Information provision in all national official languages of the country the NCP is residing in
   - Information provision in English (other foreign languages are a plus)

Principle 3: Transparency

1) NCPs provide information about their organisation and service. They try to answer all inquiries as soon as possible subject to available resources and taking into consideration domestic law.

   Indicators:
   - Information on the NCP's organisation and service, e.g. last update website
   - Reasonable periods of time, e.g.:
     - Average response time
     - Automated response that the enquiry is being processed
     - Response to every incoming enquiry

2) Taking national work processes under consideration, NCPs try to collect data about their working process, aiming to monitor their efficiency and performance.

   Indicators:
   - Customer feedback, e.g. online feedback form
   - Data collection, e.g.:
     - Average response time to a patient's request
     - Number of information requests within the scope of Directive 2011/24/EU received a year broken down by media (written, phone or person)
     - Number of information requests within the scope of Directive 2011/24/EU coming from outgoing and incoming patients

3) When this is within the NCP's competence, NCPs are transparent on the patients' rights and entitlements in accessing healthcare abroad.

   Indicators:
   - Information on health services covered under Directive 2011/24/EU, e.g.:
     - Information on health services that are included in the range of sickness benefits
     - Public detailed list of treatments subject to prior authorisation
   - Information on possible limitations to reimbursement (art. 7(9) Directive 2011/24/EU)

4) When this is within the NCP's competence, NCPs provide patients with accessible and transparent procedures regarding accessing healthcare abroad.

   Indicators:
   - All requests are dealt with in an objective, transparent and non-discriminatory way

5) When this is within the NCP's competence, NCPs provide outgoing patients with transparent procedures and clear timelines to appeal any decision regarding accessing healthcare abroad.

   Indicators:
   - Clear policy on complaints handling, e.g.:
     - Possibility of request for review of any decision within reasonable time and taking into consideration national legislation
     - Access to the complaints handling process is free of charge
     - Receipt of each complaint is notified to the complainant within reasonable time
     - Information on the further courses of procedure is provided together with each receipt of complaint
     - Complainants are given a timeline in which they may expect a decision

Principle 4: Inclusion

1) Subject to available resources, NCPs offer informed assistance to help patients with disabilities to understand and exercise their rights in accessing healthcare abroad. Information provision by NCPs is provided in formats that are easily accessible for patients with disabilities, as appropriate.

   Indicators:
   - Inclusive ways of communication, e.g.:
     - Provision of information in alternative formats, such as audio, large text, braille version,..
     - Use of pictures/ infographics to support the meaning of text
   - Extra software to increase accessibility of the NCP website for patients with disabilities, e.g.:
     - W3C Web Content Accessibility Guidelines 2.0
     - A minimum standard of screen reader compatibility, self-voicing applications, alt text for images, font size adjusters, high contrast mode, keyboard navigation, sitemap and transcripts for video and audio

2) Subject to available resources, NCPs arrange for education and training of their staff on the specific needs of patients with disabilities, taking into consideration different types of disabilities.

   Indicators:
   - Education and training of NCP staff on disability communication, including appropriate terminology and way of speaking

3) All NCPs provide information to incoming patients on the accessibility of hospitals for persons with disabilities.

   Indicators:
   - Information on the accessibility of hospitals for persons with disabilities

Principle 5: Duality

1) In accordance with Directive 2011/24/EU, NCPs make a clear distinction between information provision to outgoing patients and information provision to incoming patients.

   Indicators:
   - Distinguished information for outgoing and incoming patients, e.g.:
     - Distinguished web pages

2) NCPs facilitate the contact of patients with NCPs of other Member States.

   Indicators:

   - Contact details of other NCPs
   - Links to other NCPs' websites
   - Referral to other NCPs

Principle 6: information to outgoing patients in accordance with Directive 2011/24/EU

1) NCPs provide outgoing patients with information on patients' rights and entitlements in cross-border health services.

   Indicators:
   - Information on the legal framework for patients' rights to cross-border healthcare, e.g.:
     - Information on the patient's right to cross-border healthcare under Directive 2011/24/EU
     - Information on the possibilities to access healthcare abroad under the Social Security Regulations
     - Distinctive information on planned and unplanned treatment abroad

- Information on patients' rights to cross-border healthcare, e.g.:
    - Information on prior authorisation and which treatment is subject
    - Information on the use of prescriptions abroad as detailed in the Directive 2011/24/EU and Commission Implementing Directive 2012/52/EU
- Up-to-date information on patients' rights:
    - Legislative or regulatory amendments or revisions are followed closely and informed about

2) NCPs inform patients on the existence of two parallel routes if appropriate. They make a clear distinction on the use of the Social Security Regulations versus Directive 2011/24/EU, and the respective consequences for patients.

Indicators:

- Information on Directive 2011/24/EU and the Social Security Regulations, their scope of application and corresponding advantages and disadvantages

3) NCPs provide outgoing patients with information on the financial aspect of cross-border healthcare. They provide information on the terms and conditions for receiving reimbursement of costs and on what extra costs need to be covered by the patient him-/herself, including information on the procedures and competent authorities for accessing and determining those entitlements, as well as on the procedures for appeal and redress if patients consider that their rights have not been respected.

Indicators:

- Information on reimbursement and rates, including need of referral and info for patients insured under the social security system but living in another country

  Information on the conditions and procedure for obtaining reimbursement, e.g.:
    - Information on terms for reimbursement

4) NCPs inform patients on the importance of gathering sufficient information about the treatment and healthcare provider abroad. They refer the patient for this information to the NCP of the Member State of treatment.

Indicators:

- Information on the need to contact the NCP of the MS of treatment

5) NCPs inform patients on the importance of the transfer of medical records. Patients should be cautioned on the risk of receiving treatment without such transfer.

Indicators:

- Information on the importance of the transfer of medical records, e.g.:
    - Information on the right of access and copy of medical record

Principle 7: Information to incoming patients in accordance with Directive 2011/24/EU

1) NCPs inform patients on the importance of gathering sufficient information on needed application forms and reimbursement. They refer the patient for this information to the NCP of the Member State of affiliation.

Indicators:

- Referrals to other NCPs

2) To make patients acquainted with healthcare in their country, NCPs provide incoming patients with general information on their healthcare system, as it pertains to the individual patient as appropriate.

Indicators:

- Information on the healthcare and social security system, e.g.: Information on which care is covered by the statutory health insurance, on healthcare tariffs, on availability of treatment (including information on waiting lists)

3) To ensure safe cross-border treatment, NCPs provide incoming patients with general information on quality and safety standards enforced in their MS, as well as information on which healthcare providers are subjected to these standards.

   Indicators:
   - Information on applicable quality and safety standards, e.g.:
     - Information on bodies responsible for quality and safety standards and supervisory authorities
     - Information on which healthcare providers and healthcare facilities are subjected to these standards
   - Information on quality of care, e.g.: treatments per year per facility, patient satisfaction ratings (if any)

4) NCPs provide incoming patients with accurate information on healthcare providers and healthcare facilities established in their MS in so far as possible. NCPs provide general information on supervision and assessment of healthcare providers. Besides, NCPs inform patients on a specific provider's right to provide services or any restrictions on this practice, e.g. suspension, as available via the IMI or the NCP network.

   Indicators:
   - General information on healthcare providers, e.g.: professional liability, supervision and assessment, providers working under the statutory health insurance scheme, a specific provider's license status/ contact details where to check if a healthcare provider is licensed to practice
   - Assistance in searching for healthcare providers, e.g.:
     - Information on finding healthcare providers and healthcare facilities
     - Link to search engines for healthcare providers and healthcare facilities

5) NCPs inform incoming patients on patients' rights, complaints procedures and mechanisms for seeking remedies. Besides, NCPs provide information on the legal and administrative options available to settle disputes, including in case of harm arising from the event of cross-border healthcare, bearing in mind that this will mainly relate to referring the patient to the relevant responsible body.

   Indicators:
   - Information on patients' rights

     Information on complaint procedures and mechanisms for seeking remedies, e.g.:
     - Information on ombudsman services; on complaint procedures; on procedures to settle disputes; patient insurance and seeking damages after a medical error; on procedures for appeal and redress against a health insurer's decision; on competent authorities/courts.

Principle 8: Information provision to healthcare providers

1) NCPs provide healthcare providers with information on patients' rights and entitlements in cross-border health services under Directive 2011/24/EU and the Social Security Regulations.

   Indicators:
   - Information intended for healthcare providers, e.g.:
     - Separate section on the NCP website with information for healthcare providers
     - Information for healthcare providers on applicable legislation on cross-border healthcare
     - Information for healthcare providers on patients' rights and entitlements
     - Information for healthcare providers on documents patients have to present
     - Information for healthcare providers on equal prices for incoming patients
     - Information for healthcare providers on medical records of incoming patients
     - Information for healthcare providers on cross-border prescriptions

2) NCPs provide healthcare providers with information on their duty to provide information towards their patients according to Directive 2011/24/EU.

   Indicators:

- Information on healthcare providers' duties and responsibilities, e.g.:
    - Information on a healthcare provider's duty to help patients make an informed choice
    - Information on interpretation
    - Information on a healthcare provider's duty to provide information on treatment options
    - Information on a healthcare provider's duty to provide information on the availability, quality and safety of the healthcare they provide
    - Information on a healthcare provider's duty to provide clear invoices and information on prices
    - Information on a healthcare provider's duty to provide information on their authorisation or registration status, and their insurance cover

Principle 9: Cooperation amongst NCPs

1) NCPs should maintain partnerships amongst each other, making it easy to exchange information and build on each other's best practices.

Indicators:

- Partnerships and cooperation amongst NCPs, e.g.:
    - Meet and exchange workshops with other NCPs
    - Exchange information and best practices amongst NCPs
    - Specific dedicated communication channels (e.g. for invoices)

2) NCPs should assist each other in answering patients' inquiries and finding solutions that are the best fit for the specific patient's needs during the entire process of treatment abroad.

Indicators:

- Information exchange between the NCP of the MS of affiliation and the NCP of the MS of treatment

3) NCPs should consult with other stakeholders, such as healthcare providers, national health insurance funds, patient organisations,…

Indicators:

- Consultation with other stakeholders

ANNEX B – MAIN TRENDS BASED ON THE ONLINE SURVEY TO NCPS

Template online survey NCPs

NCPs for Cross-border Healthcare Survey 2017	
#	Question
1	The NCP of which MS do you represent?
2	What is the name of the NCP you represent?
3	What is the e-mail address of the NCP you represent?
4	How many NCPs in total are installed in your MS? Please explain when more than one
5	How is your NCP organised?
6	Is the NCP organised as a separate organ or integrated into another service that is also engaged in other matters?
7	Do you have a separate organisational division competent for outbound and inbound patients? If yes, please explain
8	How many FTEs (full-time equivalents) work for the NCP?
9	Does your NCP include a multidisciplinary team? If yes, please explain
10	How is the NCP funded? Please explain
11	Since when has the NCP been operational to the general public?
12	Since when has the website been accessible to the general public?
13	What are the possible ways of contacting the NCP?
14	Is your NCP active on social media? If yes, through which channels?
15	Do you plan to add communication channels in order to become more accessible to the general public? If yes, which channels?
16	Are you aware of any activities carried out by your MS or NCP in order to inform the general public of the existence of the NCP? If yes, please explain
17	Can you indicate the time period as well as the duration of time at which the activities referred to in the previous question were running?
18	According to your experience, are most patients aware of the existence of the NCP in your country?
19	In the past year, how many patients requested information from the NCP per month (on average)?
20	What is the average number of information requests in the course of one single cross-border healthcare event initiated by any stakeholder? Please be as specific as you can be with regard to the data gathered since your NCP function has been set up
21	What would you estimate is the average time-period it takes your NCP to process an information request?
22	Do foreign patients contact you when seeking cross-border healthcare in your country?
23	In how many languages do you provide information?
24	Please explain in which languages your NCP provides information
25	Do you make a difference in use of language for information provision to inbound or outbound patients?
26	Was the NCP website developed on the basis of W3C Web Content Accessibility Guidelines 2.0?
27	Has the NCP website been tested by visually impaired people?
28	How would you rate the level of cooperation and information sharing with stakeholders?
29	Please give a short overall explanation of the dialogues in place between the NCP and other stakeholders
30	Does your NCP provide the information requested by the patient directly or does the NCP refer the patient with their questions to other stakeholders?
31	What are the reasons for (in some cases/most of the time) preferring to refer the patient to other stakeholders?
32	Do you sometimes experience difficulties in gathering all the information needed to answer patients' questions?

NCPs for Cross-border Healthcare Survey 2017	
33	Are you aware of the official number of national patients using healthcare abroad under the Directive 2011/24/EU? If yes, please fill in the number
34	Are you aware of the official number of foreign patients using public or private healthcare in your country? If yes, please fill in the number
35	Is it possible to come to any conclusion as to the most often visited countries by outbound patients from your MS?
36	Please provide comments on the main reasons for the outbound patient's country of choice
37	Is it possible to come to any conclusion as to the typical countries of origin of inbound patients seeking cross-border healthcare in your MS?
38	Please provide comments on the main reasons for which inbound patients seek medical treatment in your MS
39	Is it possible to come to any general conclusions as to the types of treatment most frequently sought by outbound patients?
40	Is it possible to come to any general conclusions as to the types of treatment most frequently sought by inbound patients?
41	According to your experience, what is the level of awareness of patients regarding the existence of the right to receive cross-border treatment in a different MS under the Social Security Regulation (EC) No 883/2004 or the Cross-border Healthcare Directive 2011/24/EU?
42	Do you make a clear distinction between the right of cross-border healthcare and the different conditions under the Directive 2011/24/EU and under the Social Security Regulation (EC) No 883/2004 on your website and in your contact with patients?
43	Does your NCP provide information about the relevant provisions under the Social Security Regulation (EC) No 883/2004?
44	Do you experience difficulties in communicating the difference between the relevant provisions of the Directive 2011/24/EU and those of the Social Security Regulation (EC) No 883/2004?
45	Do you inform patients of the fact that the Social Security Regulation (EC) No 883/2004 will prevail in case it is more beneficial for them, unless the patient explicitly requests otherwise and explicitly asks for the applicability of the Directive 2011/24/EU?
46	Does your NCP make a distinction between information provision to inbound and outbound patients? If yes, how?
47	Do you provide general information on the healthcare system of your MS? If yes, please explain if you provide this information on your website, by telephone,…
48	Do you provide general information on the healthcare system of other MSs? If yes, please explain if you provide this information on your website, by telephone,…
49	Do most information requests concern public or private healthcare?
50	Please evaluate the frequency of information requests by patients seeking cross-border healthcare regarding the following topics: Hospitals and healthcare providers/ Quality and safety of healthcare providers/ Waiting times/ Medical documentation/ Travel and accommodation/ Reimbursement process and level of costs/ Procedures for complaint and redress/Language used
51	Does your NCP provide information on prior authorisation?
52	Has your MS opted for a system of prior authorisation in certain cases?
53	If there is a system of prior authorisation in place, what types of treatment are subject to prior authorisation in your country? Please describe briefly
54	Has a detailed list of treatments that are subject to prior authorisation been published in your country?
55	What is the time-limit for granting/refusing a prior authorisation's request?
56	Does your NCP provide information on reimbursement?
57	Is there a national tariff for treatments? Please explain
58	Are there domestic reimbursement rules other than the tariffs that are applied?
59	Are there any specific rules on tariffs that are applied for cross-border healthcare?
60	According to your experience, do health insurance companies experience difficulties in the recognition of treatments provided in another MS? For example due to different basket of treatments? Please explain

NCPs for Cross-border Healthcare Survey 2017	
61	In your view, does paying the costs of cross-border healthcare upfront under the Directive 2011/24/EU cause any difficulty for patients? Please explain
62	In order to reduce the financial burden of upfront payment for the patient, has your MS opted for a system of financial compensation directly between institutions?
63	What kind of documentation must be submitted by the patient in order to be reimbursed?
64	What is the average time period for the reimbursement of a patient's invoice starting from the delivery of the documentation?
65	Is there a possibility to cover the extra costs of the patient as well (e.g. accommodation, travel,..)? If yes, which extra costs precisely? Which documents are needed in order to have this kind of reimbursement (e.g. invoices translation of invoices,..)?
66	Are you involved in a process to monitor whether healthcare providers comply with their duties? Please explain
67	Do you have access to information on healthcare providers their right to practice or possible restrictions to this right (e.g. suspension)? If yes, please explain where you get this information
68	Does your NCP provide information on the following topics? Information on procedures for complaint and redress/ information on quality and safety standards/ information on the accessibility of hospitals in your MS for persons with disabilities/ information on how to contact other NCPs in other MSs
69	What do you consider to be the most important improvements under the Directive 2011/24/EU?
70	What do you think could be improved or developed in order to further enhance NCP practice
71	Do you have any other comments or suggestions?

1.2. Findings

Organisational context of NCPs

There are great organisational differences between NCPs, regarding:

- Single/multiple contact points;
- Host institution;
- Funding;
- Staff;
- Organisational handling incoming/ outgoing patients.

The online survey confirmed great organisational differences between NCPs. Most MSs have opted for one single NCP. In other MSs multiple contact points are established. In case of the latter, different approaches may be distinguished: two different NCPs for incoming and outgoing patients, Multiple NCPs for autonomous regions, or one "umbrella" NCP acting as coordinating NCP for multiple RCPs.

The online survey showed four main categories of host institutions for the NCP:

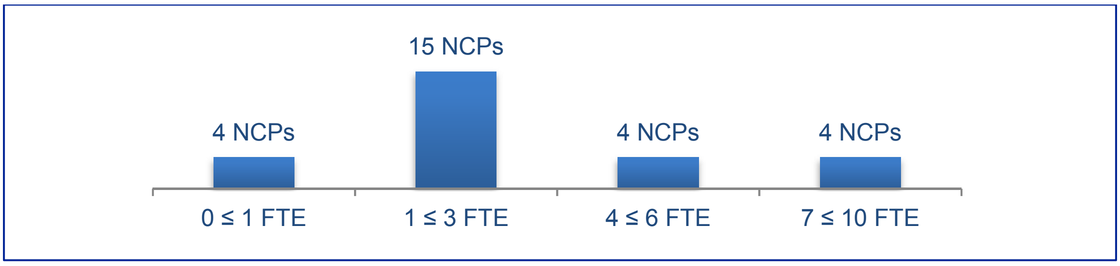
- NCP as part of a ministry;
- NCP as part of a national health insurance fund/ social health insurance institute/ NHS;
- NCP as part of an association between health insurance funds;
- NCP as part of a government agency or public service.

Almost all NCPs are integrated into a service that is also engaged in other matters, such as for example, social security, patient counselling, patients' rights, supervision and licensing of healthcare providers, quality and safety standards and health research. Nearly all overarching bodies were also engaged in matters concerning the Social Security Regulations. A number of NCPs explicitly mentioned to be also designated as liaison body between the national and foreign social security institutions under the Regulations.

The survey showed that MSs have opted for different funding strategies for NCPs. Most NCPs that answered the question stated to be funded directly from the budget of the competent ministry or through general taxation (Austria, Cyprus, Denmark, Estonia, Finland, Hungary, Italy, the Netherlands, Norway, Malta, Iceland, Ireland, Lithuania (NCP incoming patients), Luxembourg (NCP incoming patients), Portugal, Sweden). A number of NCPs is funded within the financing system of the national health insurance fund or social health insurance institute (Croatia, Lithuania (NCP outgoing patients), Poland, Romania, Slovenia), or by compensations of all health insurance funds (Czech Republic, Germany, Latvia, Slovakia). Another funding strategy mentioned was funding by different stakeholders based on a common agreed distribution key (Belgium). Finally, the survey showed that for two out of 29 NCPs there is no special funding(Greece and United Kingdom).

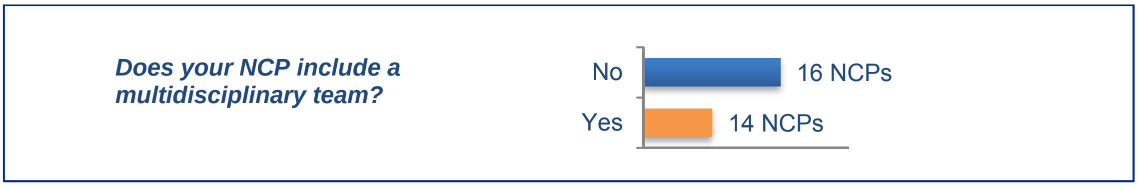
Regarding the NCP staff, the number of full-time equivalent (FTE) staff members working for the NCP function is ranging from zero in the Lithuanian NCP for incoming patients to ten in the Lithuanian NCP for outgoing patients (mean = 2). Most NCPs have between one and three FTEs. The survey shows that out of 27 NCPs, most NCPs with four or more than four FTEs are hosted in a national health insurance fund or social health insurance institute/ NHS these include the NCPs of Croatia, Estonia, Finland and Lithuania (outgoing patients)

Figure B.1 Number of FTE per NCP (*n* = 27)



On the question if the NCP staff consists of a multidisciplinary team, positive and negative answers were almost equally divided. However, slightly more NCPs stated not to include a multidisciplinary team. Out of 30 NCPs that answered the question, 14 NCPs confirmed to have representatives of different disciplines amongst their staff members, such as for example lawyers, office clerks, physicians, economists, reimbursement scheme specialists and communication counsellors. A number of NCPs highlighted that according to necessity also colleagues of other departments are involved in the NCP function.

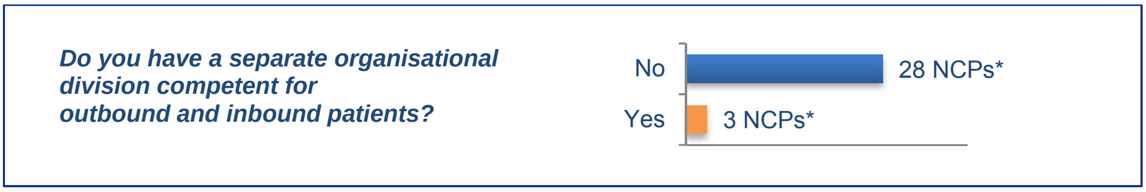
Figure B.2 Multidisciplinary NCP teams (*n* = 30)



Finally, NCPs were asked if they have separate organisational divisions competent for outgoing and incoming patients. Only four NCPs answered yes, including the NCP of Estonia, Hungary, Lithuania (outgoing patients) and Sweden (outgoing patients) (*n* = 31). The NCPs of Lithuania and Sweden stated to have separate NCPs in their country competent for outgoing and incoming patients, each with their own organisational structure and staff. The Estonian NCP, that is the single NCP in the country concerned, stated to make an internal organisational distinction by means of different staff.

However, the answers show that the question is possibly interpreted too narrowly by some respondents of MSs where there are two separate NCPs for outgoing and incoming patients. Four of such NCPs (i.e. the NCPs for incoming patients of Lithuania and Sweden as well as both NCPs of Luxembourg), have answered the question negatively, assumingly only referring to the organisational context within their own NCP and, as a result, overlooking the organisational distinction in two independent NCPs at MS level.

Figure B.3 Separate divisions for outgoing and incoming patients (*n* = 31)

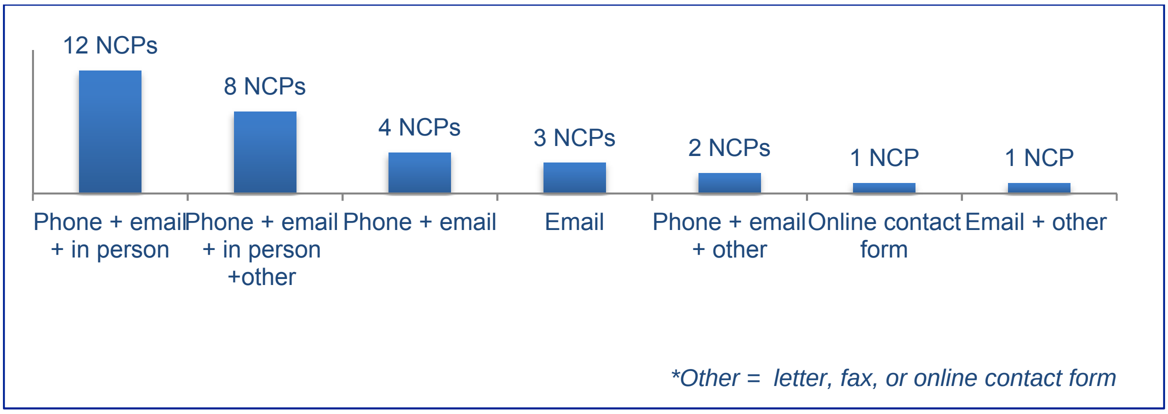


Communication channels

Most NCPs are reachable through a variety of communication channels. Besides, most NCPs also offer the possibility of in-person consultations.

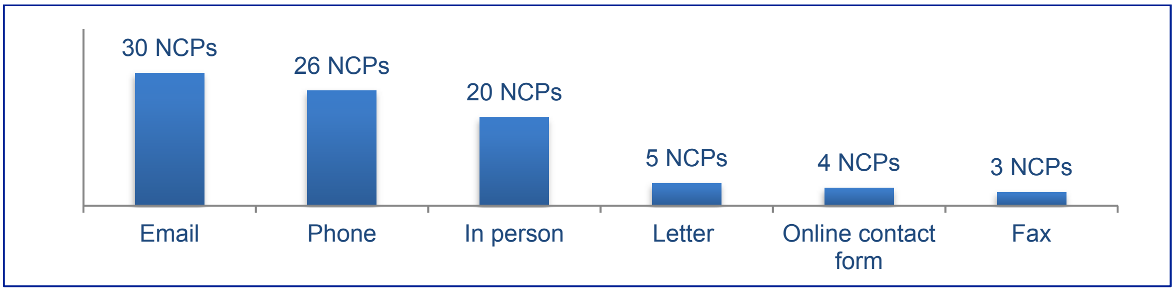
The online survey showed that, on top of the websites available for all NCPs, NCPs are reachable through a variety of communication channels. Most NCPs can be contacted via telephone, e-mail and in person. A number of NCPs is also reachable through other channels, like traditional postal letter, fax or an online contact form. Four NCPs stated to be solely accessible through one single communication channel. The NCP of Austria, Finland and Portugal answered that the only way of contacting the NCP is through e-mail. The Finnish NCP also had an exclusive phone line in the past, which was closed due to low traffic. The Dutch NCP can only be contacted through an online contact form on the NCP website.

Figure B.4 Available channels of NCPs (n = 31)



The most common means of contacting an NCP is through email. Out of 31 NCPs, all NCPs except, the NCP of the Netherlands which only provides an online contact form, indicated to provide information through email. Telephone is the second most common means and is used by 26 NCPs. Thirdly, 20 out of 30 NCPs offer the opportunity of in-person consultations at the NCP office.

Figure B.5 Means of contacting the NCP (*n* = 31)



Almost all NCPs stated to provide information in English. Besides, information is sometimes also provided in other non-official languages.

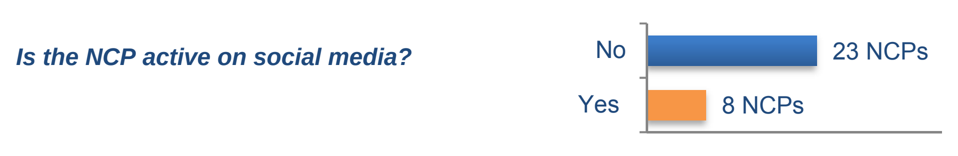
The online survey found that almost all NCPs self-report to provide information in English. NCPs were asked to enumerate the languages in which they provide information. 30 out of 31 NCPs listed English. Only the NCP of Iceland reported to only communicate in the own language. The NCP for incoming patients of Luxembourg mentioned they already communicated in English to patients, but that the NCP website was not jet available in English, which is planned for the end of 2018. The NCP of Malta reported to only provide information in English, as English is a official language. However, they do not provide information in Maltese, regardless of the fact that this is also an official language. Besides, seven NCPs indicated to also provide information in other non-official languages.

Four NCPs stated to provide personal counselling in additional languages besides the languages used on the NCP website. The NCP of Czech Republic even mentioned the use of external translation services for any other EU languages.

Only five NCPs out of 31 seem to be active on social media. Some other NCPs still prefer conventional media, like newspapers, radio and television to inform the public.

Eight out of 31 NCPs stated to be active on social media. However, the survey data showed that this number has to be nuanced. NCPs were asked to specify on which social media channels they are active. Out of the eight NCPs that answered the question positively, only five NCPs listed social media channels, like Twitter, Facebook and LinkedIn, including the NCP of Denmark, Finland, France, Iceland and Lithuania (outgoing patients). The other three NCPs clarified to be active on conventional media, such as newspapers, website, radio and television.

Figure B.6 Social media activities of NCPs (*n* = 31)



The Danish, Finnish and French NCPs stated to be active on Twitter. The Lithuanian NCP for outgoing patients and the Icelandic NCP are active on Facebook. Only the Danish NCP mentioned to have a LinkedIn profile. The Lithuanian NCP for outgoing patients mentioned to be active on "*all channels*". A quick scan of the NCP's website shows that the NCP is also active on Youtube and Instargram.[5] Of the 23 NCPs that answered not to be active on social media, the NCP of Czech Republic mentioned to have had a Facebook page in the past, which was deleted because it proved to be ineffective. The Italian NCP mentioned to have an app for consultation of healthcare abroad, called "*Se Parto per*".

NCPs were also asked if they planned to add more communication channels in the future. Eight out of 31 NCPs stated to have indeed additional channels under consideration.

Figure B.7 Additional channels under consideration (*n* = 31)

Five NCPs plan to add social media channels, of which Facebook is the most mentioned. Four NCPs intend to improve the actual channels, such as their website. The Greek NCP explicitly mentioned to plan to develop an enhanced upgrade of the English version of the NCP website. The Estonian NCP reported to be in the process of developing a self-service portal and mentioned the following: "*We are in the process of developing our own Estonian Health Insurance Fund's self-service portal to make it easier for people to contact us and also among other services have access to information regarding cross-border healthcare*".

The Norwegian NCP answered no to the question, but specified that despite of the fact that there are not yet specific plans to add more communication channels, they are considering a live chat and other technological solutions.[6]

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[5] One respondent answered to be active on all social media channels. A short analysis of the NCP website showed that the NCP concerned was active on Facebook, YouTube, Instagram and Flickr.

[6] Despite the fact that it is not mentioned in the online survey, the website analysis shows that one other NCP website already contains a live chat.

All NCPs have a website available. Already a number of NCP websites is developed on the basis of the W3C Web Content Accessibility Guidelines 2.0. However, the online survey showed there is still room for improvement.

As mentioned, all NCPs have a website available. Due to the fact that a website analysis is already conducted, the online survey did not focus on NCP websites. However, as it is of great importance those NCPs are easily accessible, the online survey did ask some questions regarding the accessibility of the website for visually impaired people.

Figure B.8 Website accessibility (*n* = 25)

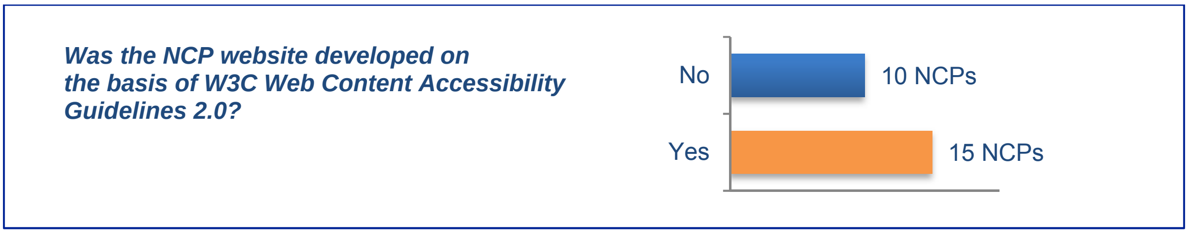
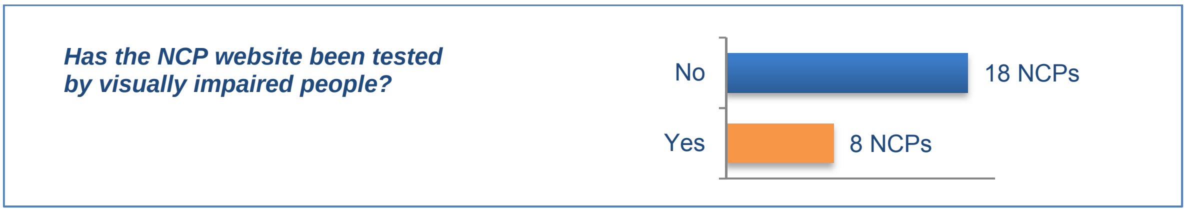


Figure B.9 Testing of the website by visually impaired people (*n* = 26)

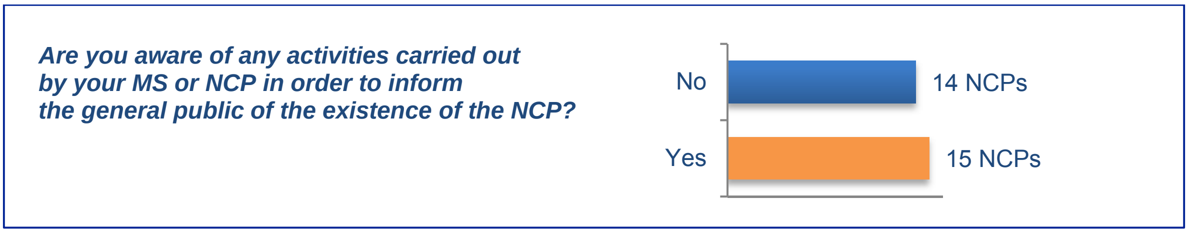


Patient awareness

Only half of the NCPs were aware of any activities carried out in order to inform the general pubic of the existence of the NCP. Besides, some NCPs referred to the information on the NCP website, which often already presupposes a level of awareness on the part of the user. This may explain why patient awareness of the existence of NCPs is generally considered to be low, as well as the limited number of information requests some NCPs receive.

15 out of 29 NCPs indicated that activities are carried out to inform the public of their existence, such as announcements in the media, press conferences, presentations, trainings for healthcare providers, and participation in public events. Two NCPs stated to have distributed a leaflet. The Polish NCP has issued two books and a briefer leaflet on the comparison between the Directive and the Social Security Regulations. The NCP of Luxembourg for outgoing patients has developed an informative leaflet explaining the NCP mission. Since 2016, the flyer is made available in most hospitals and other healthcare structures in the MS, and is resent on demand. The NCP stated that: "*A flyer concerning our missions is available in most hospitals and in many other healthcare structures. It concerns both NCP and non NCP missions. The national Health Portal and the Internet site of CNS have detailed information. Patient associations are informed. Patientevertriedung, an independent patient organisation, is offering an independent monthly information session with focus on cross-border healthcare rights (mainly focussing on reimbursement issues)*".

Figure B.10 Public campaigns (*n* = 29)



Out of the 15 NCPs that answered yes, five NCPs referred to the existence of the NCP website. However, when patients or stakeholders consult the NCP website, most of the time this already presupposes that they are aware of the existence of the NCP.

Ten out of the 15 NCPs indicated that the activities are held on a regular basis. As regards the other five NCPs, including the NCP of Belgium, Italy, Latvia, Poland, Slovakia, the activities took only place during a short period of time after the implementation of the Directive. The NCP of Portugal reported to be not aware of any activities to inform the general public on Directive 2011/24/EU, as this is not within the competence of the NCP.

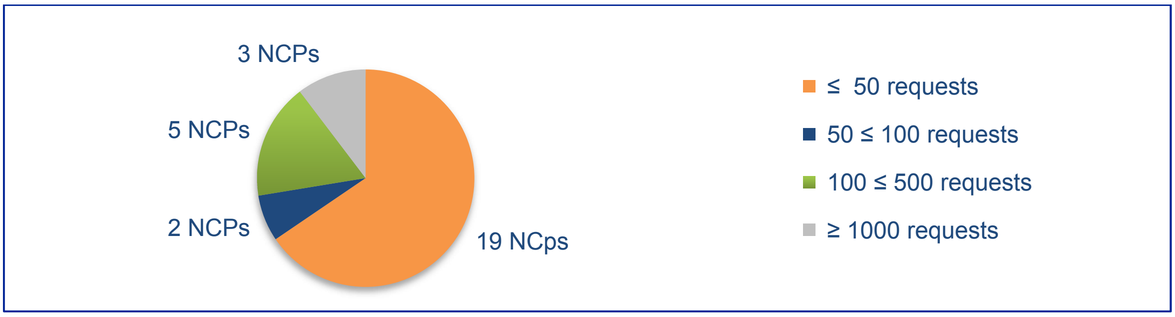
A high number of NCPs was not aware of any information campaigns targeted at the general public to raise awareness of the existence of the NCPs (14 out of 29 NCPs). This can explain why patient awareness of the existence of NCPs is generally considered to be low.

No less than 22 out of 31 NCPs experience a low level of patient awareness. More specifically, 71% of the NCPs that participated in the survey believe that most patients are not aware of their existence.

Figure B.11 Patient awareness of the existence of NCPs (*n* = 31)

The remarkably low level of patient awareness may in turn explain the limited number of information requests NCPs receive.

Figure B.12 Number of information requests per NCP (*n* = 29)

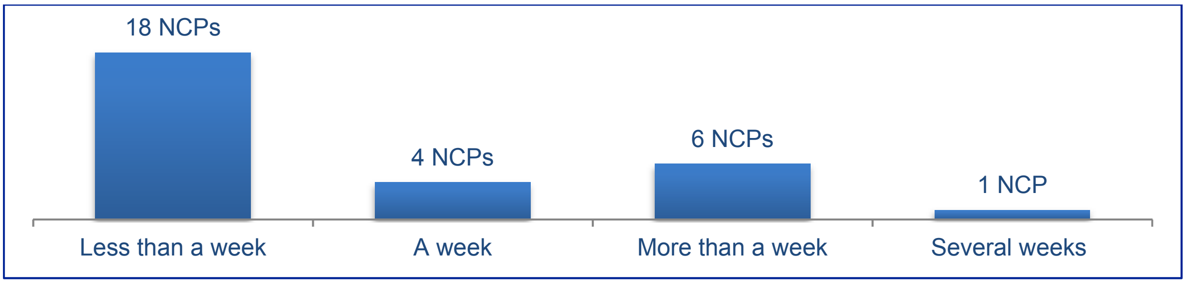


NCPs were asked how many information requests on average they received monthly in the past year. NCPs received on average 185.6 requests each month. However, great outliers can be determined (*n* = 29; range 1 to 1340; mean = 37). 19 NCPs received less than 50 requests each month (*n* = 19; range 1 to 50; mean = 14). Eight of these 19 NCPs received less than ten requests. On the contrary, three NCPs received 1000 or more requests a month.

The NCP of the UK commented that it did not answer the question explained that they rarely get any direct information request, as most patients usually get in touch with them using different routes.

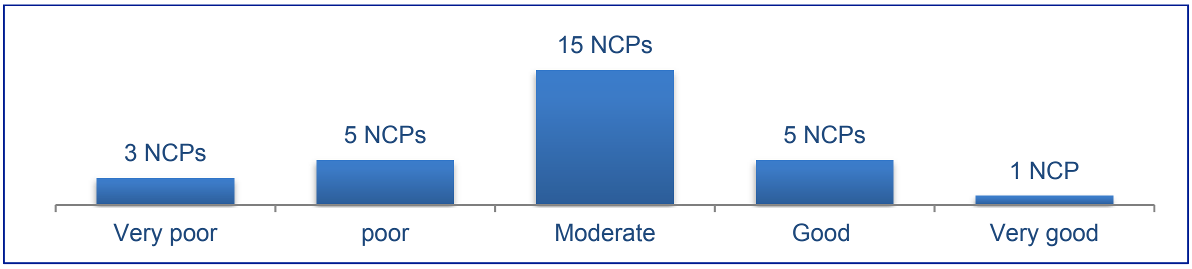
The online survey showed that for most NCPs it takes less than a week to process an information request.

Figure B.13 Estimated time period to process an information request (*n* = 29)



Next to the awareness of patients of the existence of NCPs, also the general patient awareness of the right to receive reimbursable cross-border healthcare under the Directive 2011/24/EU or the Social Security Regulations was in general not considered to be high.

Figure B.14 Patient awareness of the right on reimbursable cross-border treatment (*n* = 29)

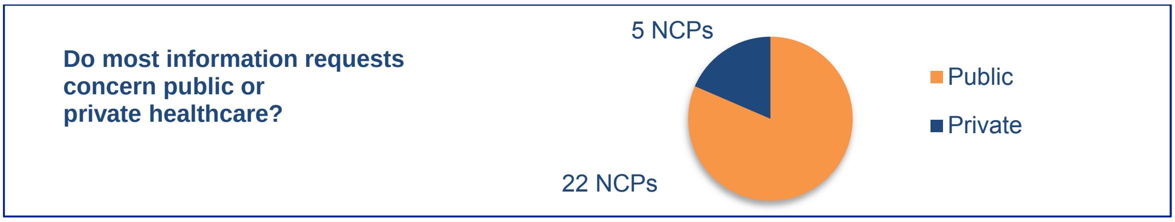


Cross-border healthcare

Most NCPs are not aware of the official number of outbound and inbound patients using cross-border healthcare under Directive 2011/24/EU. None of the NCPs was aware of the official number of incoming patients (n = 27). 11 out of 25 NCPs could provide the official number of outgoing patients, ranging from 2 to 3000 patients (mean = 414.5). The low number of NCPs answering this question, may be explained by the fact that NCPs are often not the instance in charge of collecting such data.

The online survey asked if most information requests concern public or private healthcare. Most NCPs stated to mostly receive information requests regarding public care. This seems not to be the case in Cyprus, Finland, Ireland, Latvia and Norway.

Figure B.15 Public/ private healthcare (*n* = 27)



NCPs were asked to share their opinion on the main reasons for which outbound and inbound patients seek cross-border treatment outside/in their MS. NCPs could choose out of four categories, which were chosen based on findings in literature and official data. Besides, NCPs could add other reasons.

Figure B.16 Main reasons of outbound patients (*n* = 29)

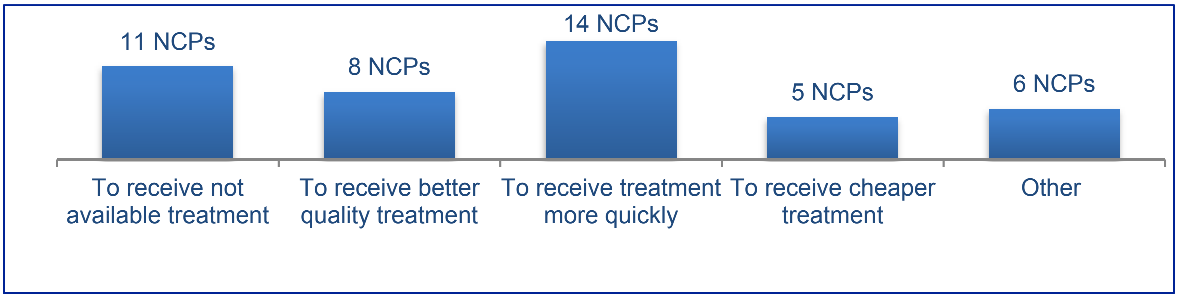
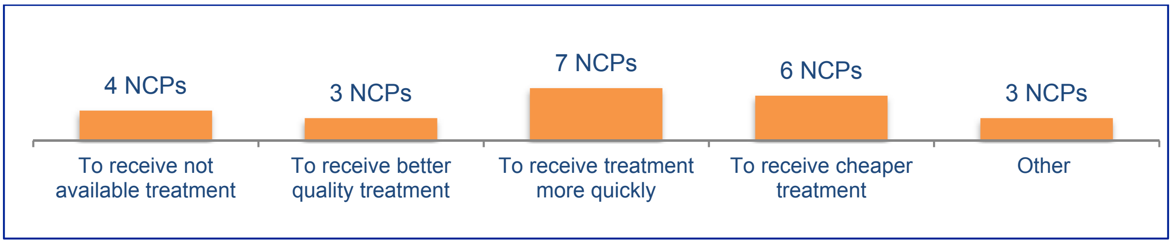


Figure B.17 Main reasons of inbound patients (*n* = 27)

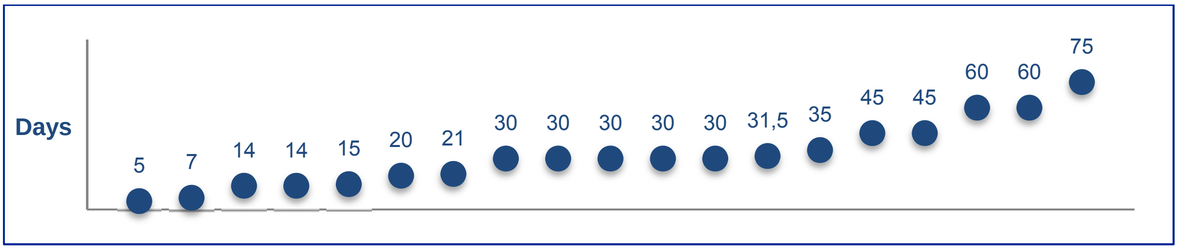


NCPs experience that both outgoing and incoming patients most often travel abroad to receive treatment more quickly. Other reasons that were mentioned for outgoing patients to receive cross-border treatment include treatment in private facilities, medically necessary treatment, familiarity with healthcare systems abroad, to receive treatment closer to family members, and the activity of companies and agencies which coordinate and organise the access to healthcare abroad. For incoming patients, the reasons additionally mentioned were private stays, medically necessary treatment, commuting from neighbouring countries and medical tourism. The NCPs of Estonia and Czech Republic explicitly mentioned that there were no official data available of incoming patients. The Belgian NCP indicated to not have such specific information available both for incoming and outgoing patients.

25 out of 31 NCPs indicated that their MS has opted for a system of prior authorisation. The NCP of the Czech Republic, that did not opt for a system of prior authorisation, explicitly stated that it would be very useful to have a detailed list of prior authorisation measures in other MSs. The Directive 2011/24/EU requires that each state has to make publicly available which healthcare is subject to prior authorisation. However, only 13 out of 30 NCPs indicated that a detailed list of treatments subjected to prior authorisation was published in their MS.

The survey showed that on average it takes 31 days to grant or refuse a request for prior authorisation (*n* = 19). The NCP of Luxembourg that is competent for outgoing patients answered that there is no time-limit in their MS. The Dutch and Austrian NCP indicated to not have such information available.

Figure B.18 Time-limit for granting / refusing a request of prior authorisation (*n* = 19)

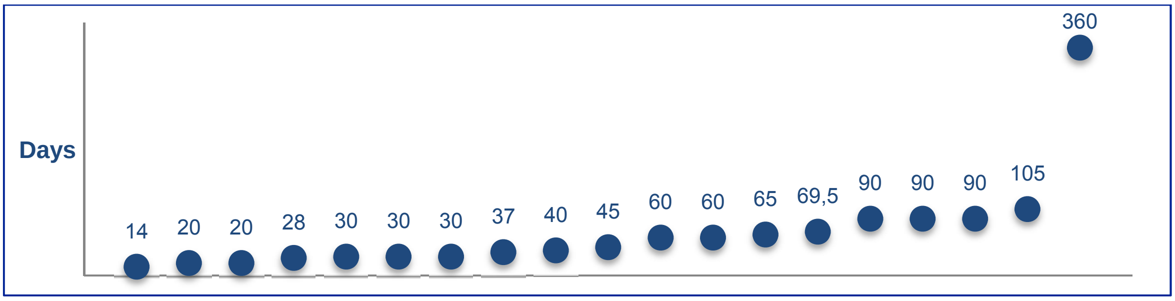


The survey also asked some questions regarding reimbursement. 10 out of 24 NCPs stated that health insurance companies experience difficulties in the recognition of treatments provided in another MS. Most common reasons mentioned were difficulties resulting from different invoicing systems, making it often challenging for health insurers to determine which specific healthcare was provided. NCPs also stated that the use of different DRG coding systems is experienced as a significant barrier. The NCP of Ireland mentioned the need for a means of cross-matching DRG codes of different countries, stating that "*Ideally there would be a means of inputting a DRG code from one country for cross match with another country*".

NCPs were also asked which documents must be submitted by patients in order to receive reimbursement. Most frequently returning answers include prior authorisation forms, referrals, medical records of the treatment, prescriptions of medicines, and original invoices, including bills for prescriptions. The French NCP, the Estonian NCP, the Romanian NCP, Hungarian NCP and the Italian NCP mentioned the need to present an official application form for reimbursement. The NCP of Ireland also reported the need to present a GP referral letter or waiting list letter, an original invoice, proof of travel and an optional pro-forma invoice. The NCP of Czech Republic mentioned the need to present a translation of invoice in cases where the Czech Health Insurance Fund does not know the original language. Also the NCP of Luxembourg listed the need to present bills in a language understandable for the clerk. The NCP of Norway also mentioned the need to present a proof of the authorisation status of the healthcare provider abroad. The NCP of Greece indicated the need to present amongst others a proof of the professional status of the foreign healthcare provider, as well as documentation on "*the patient's history (in cases of hospital care) and in cases of patients with certified disabilities who have received relevant prior authorisation, proof of payment for travelling and accommodation expenses*". The NCP of Portugal stated that the patient amongst other things has to provide information from the family doctor confirming the need for the treatment. The Romanian NCP included the need of a referral from a Romanian healthcare professional which has a contractual relationship with the health insurance house.

The survey showed that on average it takes 45 days for patients to obtain reimbursement for healthcare received abroad (mean; *n* = 19). However, for three NCPs the time-limit mentioned is only applicable when there is no need for gathering additional information. In some cases, specific time frames have to be respected. Other NCPs gave the time-limit that was handled in practice. Also here, it should be kept in mind that NCPs are not always the instance competent for collecting such data.

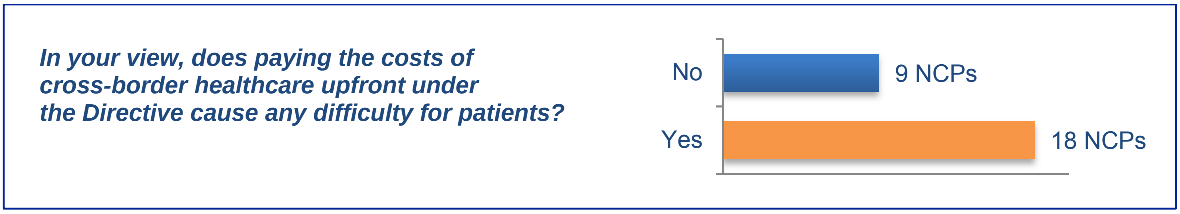
Figure B.19 Time-limit for reimbursement (*n* = 19)



Two out of three NCPs identified upfront payment as an impediment.
NCP of Luxembourg: *"Directive 2011/24/EU: medicine for the rich, not the poor"*
NCP of Estonia: "*Yes, because the costs for different services are much higher in other MSs. Patients who do not contact us beforehand to find out in what amount they most likely would be reimbursed are unsatisfied with the reimbursement sum".*
NCP of Germany: "*Often the costs are high and the patient does not exactly know how much he will get reimbursed".*
NCP of Greece*: "Mostly the patients resent the bureaucracy (translated and authenticated docs etc.) involved and the time they have to anticipate reimbursement."*

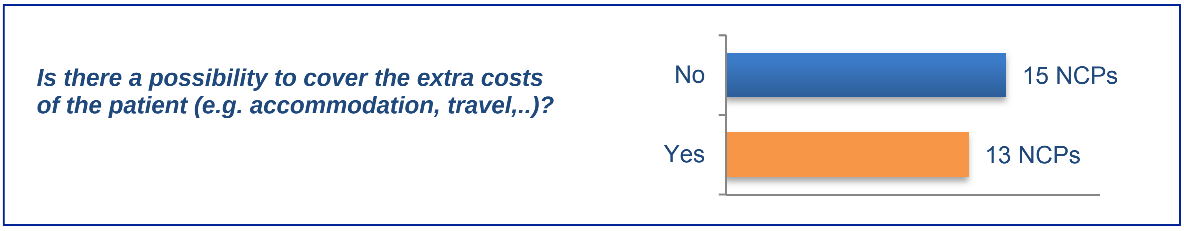
Two out of three NCPs identified upfront payment as a barrier for patients to receive cross-border treatment under Directive 2011/24/EU (*n* = 27). Only three out of 28 NCPs stated that in order to reduce the financial burden of upfront payment, there was a system in place of financial compensation directly between institutions. More specifically, such system is provided in Belgium, Germany and France. The French NCP stated that "*France has submitted certain heavy treatments with prior authorisation and the insured must obtain an S2 form. Therefore, if this form is granted, the patient does not have to advance the expenses, except for the possible co-payment. In addition, France has concluded certain cross-border agreements with Belgium, Germany, Switzerland and Spain containing specific financial provisions: settlement of expenses by the* *social security funds of the country of care on behalf of France or reimbursement of health care providers directly by the French social security funds, sometimes on the basis of negotiated rates"*. The NCP of Germany mentioned contracts between healthcare insurers and healthcare providers abroad, resulting in third party payments. The Czech NCP stated that in their point of view such system is legally not possible.

Figure B.20 Upfront payment (*n* = 27)



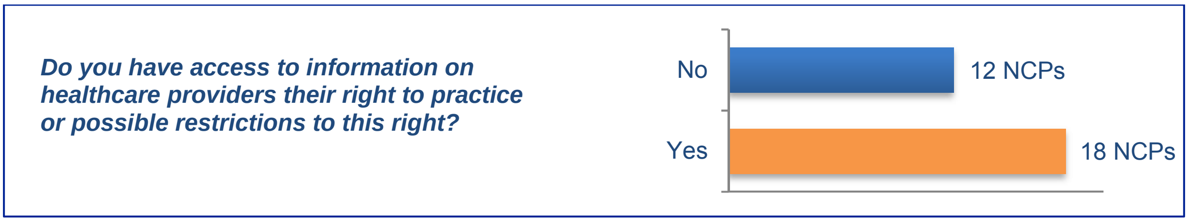
13 out of 28 NCPs indicated that there is a possibility in their MS to cover extra costs for travel and accommodation. Two NCPs indicated that this was depending on the financial situation of the patient. The NCP of Greece mentioned that this was only possible for patients with a certified disability, after prior authorisation based on case-by-case assessment.

Figure B.21 Reimbursement of extra costs (*n* = 28)



The online survey showed that 18 out of 30 NCPs have access to information on a healthcare provider's right to practice or possible restrictions placed on this right. Six NCPs mentioned they do not have direct access to such information but that they can request such information from the competent authorities. The Irish NCP mentioned the use of the IMI system to request information on healthcare providers abroad. Other NCPs have access to the information through public registers or online databases.

Figure B.22 Healthcare providers' right to practice (*n* = 30)



Information provision

Almost all NCPs indicate to provide information on the Social Security Regulations. Besides, most NCPs state to make a clear distinction between the right on cross-border treatment under Directive 2011/24/EU and the Social Security Regulations. However, a high number of NCPs experience difficulties in providing information on this distinction.

It is almost impossible to treat Directive 2011/24/EU independently from the Social Security Regulations. NCPs therefore also have the duty to inform patients on the differences between both legal instruments. Besides, NCPs have to draw patients' attention to the priority rule the EU legislator has installed in favour of the Regulations, more specifically, to the fact that when the conditions for its application are met, the Social Security Regulations will prevail (unless the patient specifically requests otherwise).

Figure B.23 Information on the Social Security Regulations (*n* = 31)

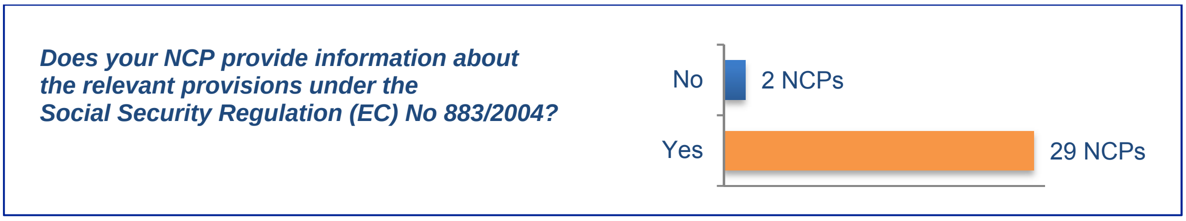
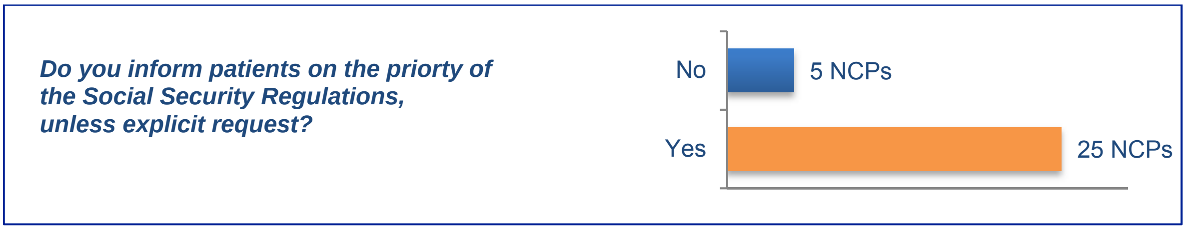


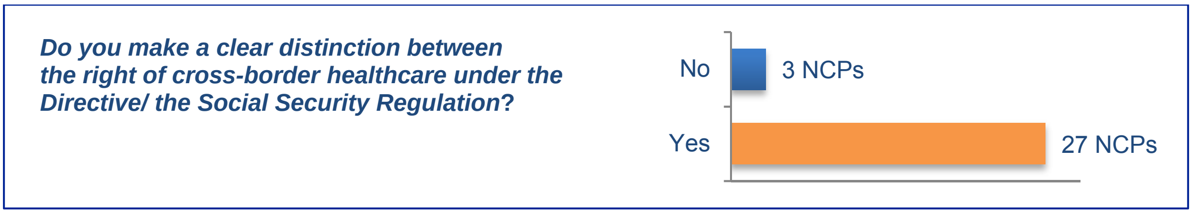
Figure B.24 Priority of the Social Security Regulations (*n* = 30)



The survey showed that almost all NCPs stated to provide information on the Social Security Regulations. Five out of six NCPs also indicated to inform patients on the priority of the Social Security Regulations, unless specifically requested otherwise by the patient.

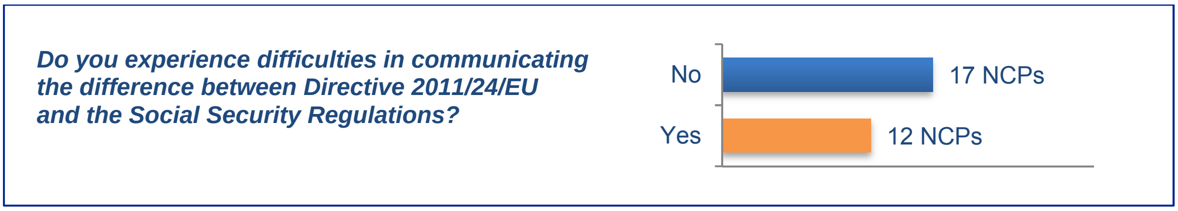
Besides, 27 out of 30 NCPs declared to make a clear distinction between the right on cross-border treatment and the different conditions under Directive 2011/24/EU and under the Regulations, both on the NCP website as in their direct contact with patients.

Figure B.25 Distinction between Directive 2011/24/EU and the Social Security Regulations (*n* = 30)



However, on the question if the NCP sometimes experienced difficulties in communicating the differences between the relevant provisions of Directive 2011/24/EU and those of the Social Security Regulations, 12 out of 29 NCPs answered yes. In light of the legal requirements under Directive 2011/24/EU, this number may be considered as very high and striking.

Figure B.26 Difficulties in making a distinction between Directive 2011/24/EU and the Social Security Regulations (*n* = 29)



NCPs fulfil a twofold function as NCP of the MS of affiliation and NCP of the MS of treatment.

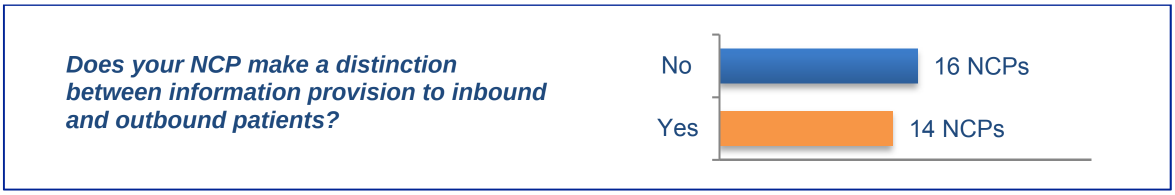
NCPs have an information duty towards both incoming and outgoing patients. The survey showed that almost all NCPs are indeed also contacted by foreign patients seeking cross-border healthcare in their country. Three NCPs, including the NCPs for incoming patients of Lithuania and Sweden, as well as the Irish NCP stated to be solely contacted by outgoing patients. Thus, only two of them are NCPs only competent for outbound patients.

Figure B.27 Information requests of incoming patients (*n* = 30)

As the Directive 2011/24/EU makes a clear distinction between information duties of the NCP of the MS of affiliation and information duties of the NCP of the MS of treatment, NCPs were also asked if they make a distinction between information provision to inbound patients and outbound patients.

14 out of 30 NCPs stated to make a distinction between incoming and outgoing patients. NCPs referred most often to different parts on the NCP website with information dedicated to inbound or outbound patients. The NCP of Greece explicitly mentioned that the part in the national language, covering information to outbound patients, was more detailed than the English version intended for incoming patients. Other NCPs referred to the existence of two separate NCPs, one competent for incoming patients and the other for outgoing patients.

Figure B.28 Distinction in information provision to incoming and outgoing patients (*n* = 30)



Most MSs provide patients with general information on their own healthcare system. Almost all NCPs indicated that information on their own healthcare system is provided on the NCP website and through other communication channels. Only ten out of 31 NCPs also provide general information on the healthcare systems of other MSs. The French, Finnish and United Kingdom NCP indicated that information on healthcare systems of other MSs and foreign social security schemes was provided on the NCP website itself. Other NCPs answered to refer the patient for more information to the NCP of other MSs concerned. They also provide contact details and links of other NCPs on their website.

Figure B.29 Information on the own healthcare system (*n* = 31)

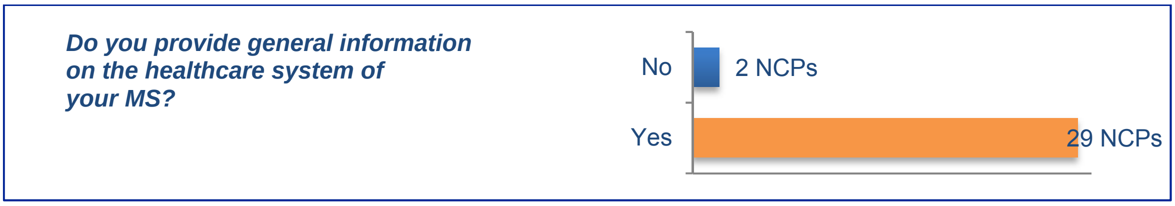
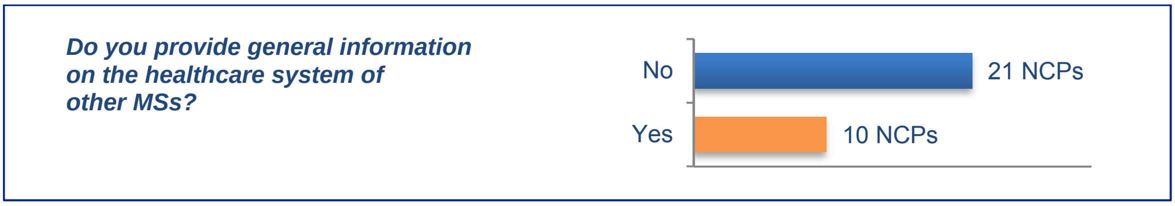


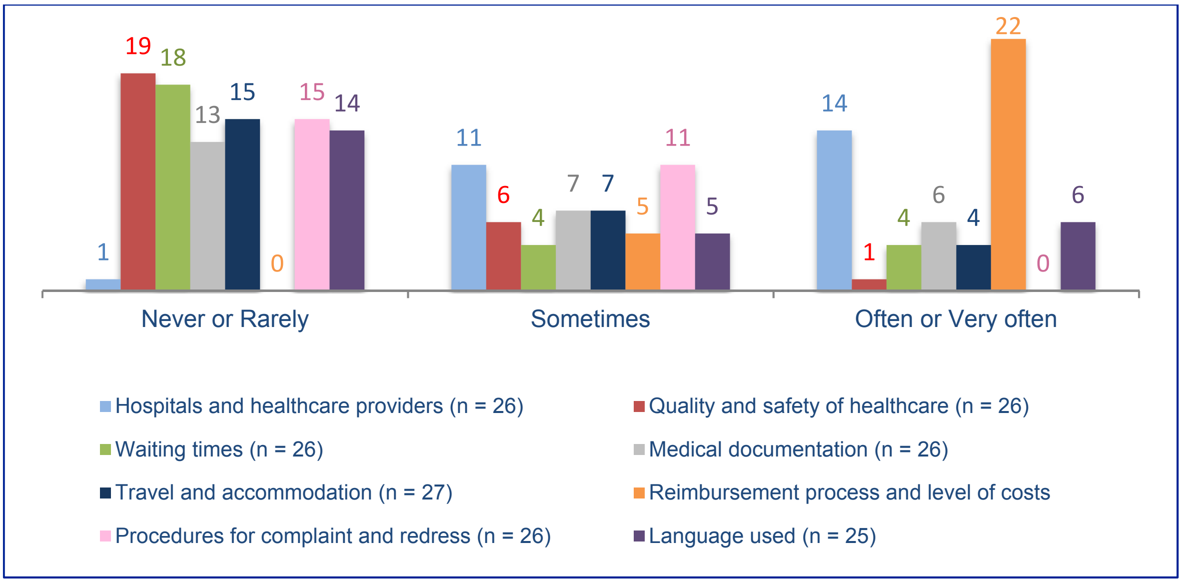
Figure B.30 Information on healthcare systems of other MSs (*n* = 31)



One of the general principles of the Directive is that appropriate information on all essential aspects of cross-border healthcare is necessary in order to enable patients to exercise their right to treatment abroad. NCPs play a crucial role in such information provision. However, one out of two NCPs declares to sometimes experience difficulties in gathering all the information themselves.

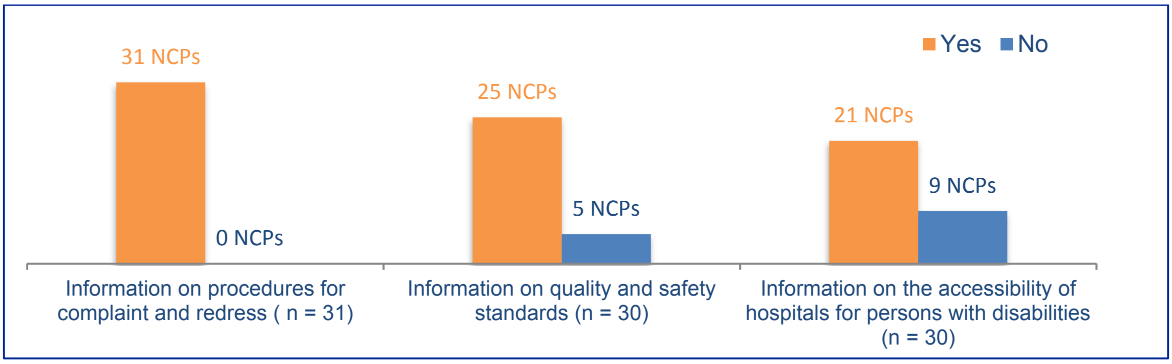
The survey showed that NCPs receive information requests regarding different topics. NCPs seem to receive a high number of requests on reimbursement and costs. Requests on hospitals and healthcare providers also seem to occur frequently. On the contrary, 19 out of 26 NCPs said to never or rarely receive any request on quality and patient safety. Also information requests on waiting times, on travel and accommodation and on procedures for complaint and redress seem to be rather exceptional.

Figure B.31 Frequency of information requests regarding different topics



NCPs were also asked if they do provide information on procedures for complaint and redress, quality and safety standards, and on the accessibility of hospitals for persons with disabilities. 5 out of 30 NCPs do not provide information on quality and safety standards (i.e. Denmark, Latvia, Lithuania as well as both the Luxembourgish NCP for incoming and outgoing patients answered no). Besides, 9 NCPs indicated they do not provide information on the accessibility of hospitals (i.e. Denmark, Estonia, Finland, Luxembourg, Netherlands, Portugal, Sweden and both NCPs of Lithuania). The latter can be considered as a high number, considering the specific obligation to provide such information under Directive 2011/24/EU.

Figure B.32 Information provision on procedures for complaint and redress, quality and safety standards and accessibility of hospitals



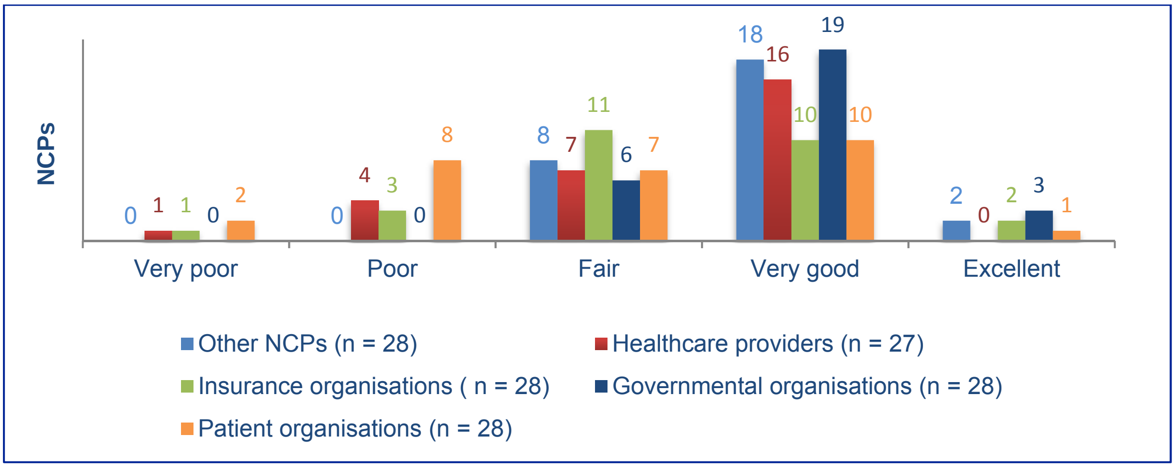
The survey showed that one out of two NCPs sometimes experiences difficulties in gathering information needed to answer patients' questions. Four NCPs stated to even often encounter such difficulties.

Figure B.33 Difficulties in information gathering (*n* = 30)

Cooperation

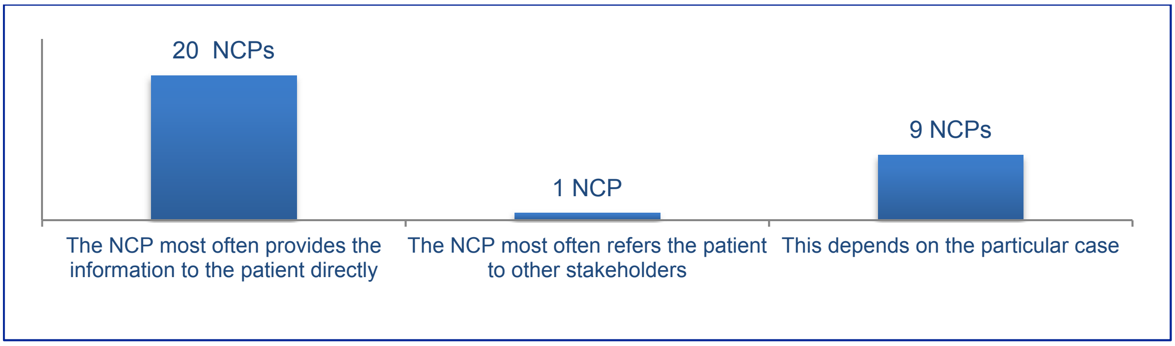
NCPs explained in general to cooperate well with other stakeholders. However, 10 out of 28 NCPs evaluated the cooperation with patient organisations negatively. NCPs seem to be most satisfied with the level and form of cooperation with other NCPs and with governmental organisations.

Figure B.34 Cooperation with other stakeholders



NCPs were asked if they most often refer patients directly to other stakeholders or, on the contrary, provide the information directly to the patient. Only one NCP answered the latter. Two out of three NCPs inform the patients themselves (*n* = 30).

Figure B.35 Referring of the patient to other stakeholders (*n* = 30)



NCP views and recommendations

NCPs overall experience great improvements under Directive 2011/24/EU. However, they also consider there is still room for improvement regarding comparability of invoices, NCP websites, visibility of NCPs and patient awareness, as well as regarding cooperation and information exchange between NCP.

At the end of the survey, NCPs were asked to share some final views and recommendations.

NCPs were asked what they considered as most important improvements under Directive 2011/24/EU. Most NCPs indeed experienced some great improvements:

✓ *“The contact possibilities to private healthcare providers in another MS and the possibility to get routing information about crossborder healthcare possibilities from the NCPs”;*
✓ *”The existence of a rather clear legal basis for healthcare abroad”;*
✓ *“The fact that the Directive clarified the possibilities for treatment abroad”;*
✓ *“Reimbursement of all outpatient care without prior authorisation”; “The possibility of receiving care more easily in case of rare diseases”;*
✓ *“European Reference Networks, so that persons with rare diseases may receive help in other MS by their experience, specifications and scientific work”;*
✓ *“The right to choose one's healthcare provider, whether it is in one's own country or across border. The right to have financial assistance from one's own national healthcare service or ministry for health for healthcare undertaken in another country. This has improved the capacity to choose alternative treatment options, alternative healthcare providers and professionals whom one may have more trust, through information they might have gathered or whom they might have consulted previously either through direct consultation or via e-mail or other means of communication”;*
✓ *“The possibility to transfer knowledge of medical professionals among all EU” ” “The possibility to get more specific healthcare for the patient with rare diseases”;*
✓ *”The creation of a basic set of patients’ rights at EU level” “the clarification of the obligations of the Member States of affiliation, on the one hand, and the Member State of Treatment, on the other hand”;*
✓ *“Faster access to healthcare services”;*
✓ *“The potential benefits of cross-border cooperation regarding prescriptions, e-health, ERNs,..”;*
✓ *“Free mobility of patients; choice of public or private providers; NCP network; familiarisation with health systems of other MS”;*
✓ …

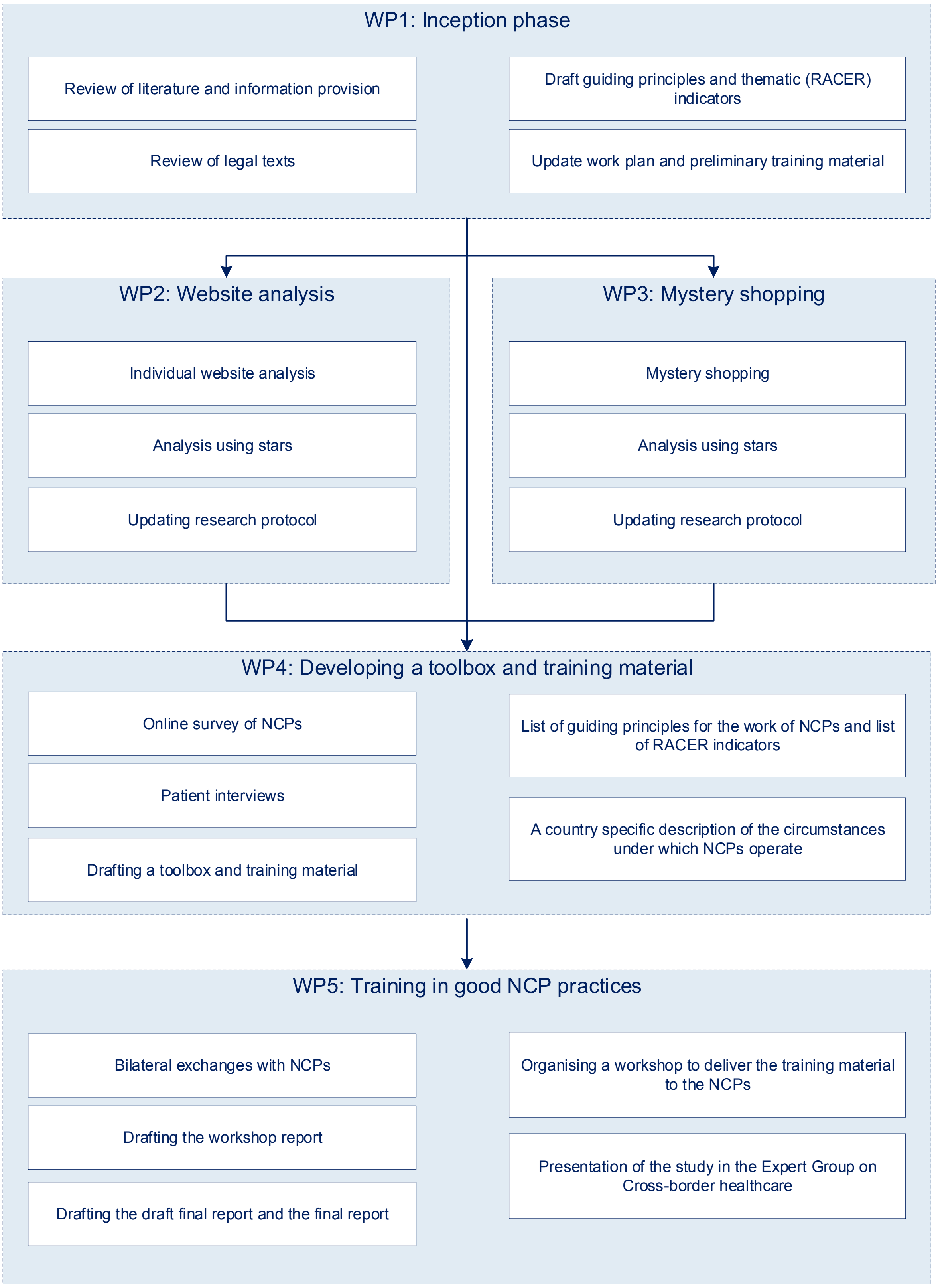
Two NCPs consider there are no improvements under Directive 2011/24/EU. The Czech NCP refers to the fact that cross-border treatment was already possible under the Social Security Regulations. A RCP of Denmark stated that cross-border healthcare was not considered preferable as healthcare in the own MS is already of a very high standard and besides patients most often prefer to communicate in their own language when receiving healthcare.

Some NCPs also mentioned some remaining impediments and possible improvements to facilitate cross-border healthcare and enhance NCP practice:

X *“Involve the NCPs in the routing of patients with rare diseases in cooperation with the ERN and making the NCP´s more public”;*
X *“The standardisation of invoices for reimbursement process (mandatory data and standard codification of the procedures)”;*
X *“Reimbursement procedures”;*
X *“If a system of reconciling DRG codes used by each country could be developed this would be a significant help to providers abroad for patients”;*
X *“Sharing information of accessibility of special health care service on EU common portals”;*
X *“Difficulties that patients encounter in finding a health professional or health facility in another European country and in finding reliable information about the quality and/or safety of care: The sites of the national contact points are not always translated into English and they do not give direct access to databases of providers but only provide links to internal and non-translated sites” “The completeness of the websites of our partners in the different European countries” “The information provided on the various websites of foreign NCPs is often succinct, general and rarely discloses the concrete information that patients need”;*
X *“Language barriers”;*
X *“We have felt that we are lacking knowledge about other MSs health care systems”;*
X *“More international exchanges of health system functioning”;*
X *“Better cooperation between NCP's of all EU Member States”;*
X *“More efficient cooperation with healthcare providers and patients' organizations”;*

- *"More cooperation between NCPs. Not only meetings where all NCPs are present, but meetings between just a couple of NCPs would be a learning experience";*
- *"Better sharing of information among NCPs. IT systems could help (for example, website or IT based forum) to share actual information of NCPs";*
- *"I think that overall the NCP practice is good, but we have felt that we are lacking knowledge about other Member States health care systems. It would be also good to have a platform to exchange thoughts from time to time in certain cases" "Improve and develop our own NCP function and increase the awareness of our insured persons";*
- *"Nationally, there is the need for further HR support and funding for the communication of the Directive's scope and objectives to the stakeholders involved" "NCPs could team up to be involved in projects collecting info from all MS on priority issues such as quality and safety, a summary/presentation of the national health system, using e.g. checklists or templates, which would feed into the websites of the NCPs network";*
- *"In future we need to improve NCPs as a multidisciplinary team, which can give people high quality, instant answers and recommendations";*
- *"Raise awareness among the general public on the existence of the NCPs and their role (i.e. explain very well what they can do but also be clear what not)" "At this moment, I have the feeling we find ourselves in a vicious circle: as the NCPs are not known, they do not receive many questions; as the NCPs do not receive many questions, stakeholders are not inclined to invest in the improvement of the functioning of the NCPs,... ";*
- *"Create better visibility via campaigns".*
- *...*

ANNEX C – OVERARCHING RESEARCH PROTOCOL



ANNEX D – UPDATED WEBSITE ANALYSIS METHODOLOGY (WP2)

The methodology for the website analysis is based on the Evaluative study in which 48 Specific Analytical Items were developed to structure the website analysis.[7] According to the Evaluative study, the purpose of these SAIs was to "*analyse the website design, its functionalities, its ease of access, and as well as to gauge whether a citizen would be able to find the information required under the Directive and what is necessary to access cross-border healthcare services*".

Based on the analysis of the legal texts (WP1), the literature review (WP1), a review of studies on quality assessment of websites aimed at patients[8,9], and the pilot, we have updated the methodology for the website analysis.

Categories

The website analysis looks at nine categories, with three of these focusing on the website itself – technical elements, accessibility, usability – and six categories focused on the content of the website – general information, healthcare providers, patients' rights, prior authorization, quality and safety standards, entitlement for reimbursement of costs -.

Language

The SAIs from the categories that focus on the website itself should be analysed using the English language website (where available). The content SAIs aimed at outbound patients should be analysed using the native language website, and the SAIs aimed at inbound patients using the English language website.

Table 1 shows the SAI to be analysed in English in blue and the SAIs to be analysed in the native language(s) in green. The SAIs that do not have a background colour, are the SAIs we recommend analysing by using both the English and the native language(s) websites. These SAIs include answer categories that show whether the information was available in English, the native language(s) or both.

Table D.1 SAIs by language in which they should be analysed

SAI category	Specific Analytical Item
A. Technical elements	1. Independence of the NCP's address; 2. Presence of background information about the website; 3. Presence of NCP e-mail address; 4. Presence of the NCP office address; 5. Presence of NCP telephone numbers; 6. Presence of other contact information (e.g. social media); 7. Presence of contact details of other NCPs (previously: presence of contact details for other NCPs); 8. Date of the last update of the website (previously: last date of update of information).
B. Accessibility	9. Order in search (Google) for: "NCP + the name of the MS"; 10. Order in search (Google) for: "NCP + healthcare + the name of the MS"; 11. Which website opens when clicking on the EU DG Sanco NCP's contact list; 12. Ease of opening the website (previously: accessibility); 13. The availability of the website in different languages, even if only partly translated. (native / English/other); 14. Availability of options for people with decreased sensory functioning (e.g. read-out-loud, increased text size, different colour mode).
C. Usability	15. Presence of most visited pages; 16. Presence of frequently asked questions; 17. Presence of internal search engine;

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[7] Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, http://ec.europa.eu/health//sites/health/files/cross_border_care/docs/2015_evaluative_study_frep_en.pdf.

[8] Siddhanamatha HR et al. Quality assessment of websites providing educational content for patients with rheumatoid arthritis. Seminars in Arthritis and Rheumatism 2017.

[9] Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. J AM Med Assoc 2002;287:2691-700.

SAI category	Specific Analytical Item
	18. Presence of Media Library containing video's regarding cross-border healthcare; 19. Visual appeal and layout (scored on the use of menus, (sub)headings, illustrations, and overall attractiveness).
D. General information	20. Information for inbound patients. In English (previously: information on inbound patients; 21. Information for outbound patients. In the native language(s) (previously: information on outbound patients; 22. Information that clarifies the differences between EU Regulation 883/2004 and the Directive 2011/24/EU (previously: Clarifying differentiating EU policies - Specifically the Regulation 883/2004 and the Directive 2011/24/EU.); 23. Information on patients' rights regarding cross-border care (previously: patients' rights to seek treatment in other EU countries).
E. Healthcare providers	24. A description of the health system; 25. Information on healthcare providers (e.g. available services); 26. Contact details of national healthcare providers; 27. Presence of tools to find a specific national healthcare provider.
F. Patients’ rights	28. Information on the definition of waiting time; 29. Information on patients' rights in case of undue delay; 30. Information on patients' rights in the event of harm; 31. Information on access to hospitals for disabled patients; 32. Information on how to access electronic medical records; 33. Information on mechanisms to settle disputes (e.g. reimbursement issues); 34. Information on rare diseases for patients with a rare disease without references to ERNs (European Reference Networks); 35. Information on ERNs for patients with a rare disease; 36. Information on complaint procedures in case of follow-up treatment issues.
G. Prior authorisation	37. Presence of information on which treatments require prior authorisation; 38. Presence of list of treatments requiring prior authorisation; 39. Information on procedures to obtain the reimbursement; 40. Presence of forms for prior authorisation; 41. Presence of information on time period for requests to be dealt with.
H. Quality and safety standards	42. Information on national legislation and policies regarding patient safety; 43. Information on medical certifications and qualifications required by the national healthcare system; 44. Information on the national quality strategy; 45. Information on compliance checks and regulatory activity with respect to quality and safety standards (e.g. hospital inspection bodies, etc.); 46. Information on quality measurements/indicators for healthcare providers.
I. Entitlement for reimbursement of costs	47. Information on which treatments are reimbursed; 48. Information on which treatments are not to be reimbursed; 49. Information on requirements for the recognition of invoices/clinical information; 50. Information on time period for reimbursement; 51. Information regarding payment tools for reimbursement; 52. Information on type of tariffs to be applied.

Practical tips for website analysis

- Prior to starting the analysis of multiple websites, organise a small pilot analysing two to three websites. This will give the researcher(s) the chance to familiarise themselves with the SAIs and to discuss any differences in interpretation of SAIs;
- Ensure all researchers involved in the websites analysis take sufficient and clear notes, to ensure transparency of the analysis;
- Involve researchers without a background in IT or computer science in conducting the website analysis, to ensure the researchers look at the NCP websites in a manner similar to the average patient.

ANNEX E – EMAIL TEMPLATES (WP3)

Box E.1 Email template Scenario 1

Subject: Seeking reconstructive surgery abroad

Dear Sir or Madam,

I am writing to you to find out more about the possibility to travel to another EU country to undergo surgery. My younger brother suffered an accident as a child and as a result has third degree burns on his shoulder. He is now a young adult and would like to undergo reconstructive surgery to improve the scarring and function of his shoulder. We were thinking about whether he could travel abroad for this as we have heard that there are some private specialists that are very well known for the type of reconstructive surgery my brother would need. Before we go any further with our research into this possibility, I was hoping to find out more about the practicalities of this option.

Is my brother entitled to receive this hospital treatment in our country? Is treatment available here? What is a normal waiting time for this type of surgery?

Is it possible to seek reconstructive surgery privately under the right to go to another EU country?

Does my brother need any kind of authorisation before he can travel abroad to have this kind of surgery? If so, where or how should we enquire about this authorisation and how long would it take for me to get it?

If my brother is a good candidate for the reconstructive surgery with a private specialist, will he be reimbursed for it? How much could he be expected to be reimbursed?

Related to this, does he have to pay upfront? What about any extra costs, such as transport costs, can he be reimbursed for those?

What paperwork would be needed to get reimbursed any of these costs and how would I go about claiming this reimbursement? Would you be able to support me in arranging the paperwork for my brother?

Do we need a referral?

How can we have access to my brother's medical records? How much would this cost us?

Will follow-up care be provided at home or abroad?

We were wondering if you have any reports, flyers or videos that I could share with my younger brother about travelling abroad for surgery? Do you have any information from other patients that have done this?

Is there any other information that we should be aware of before seeking this surgery abroad?

Many thanks for any help and information you can give us – it is very helpful that this information point exists.

Could you please provide a telephone number where it is possible to contact you?

Warm Regards,

Box E.2 Email template Scenario 2

Subject: Information about a hip replacement in another country

Dear Sir/Madam,

I am a pensioner living here in [Country X], but I spent all of my working life in [Country Y[10]]. I am interested in the possibility of seeking a hip replacement operation in back in the country where I worked all my life. I still have strong connections of family and friends there who could help me during my recovery. I was thinking of approaching some of the larger public hospitals to find out how long the waiting list would be and find out if I can be placed on it. I have some questions about how the right to travel abroad works before I start getting in touch with these public hospitals.

Is it possible that I have the right to go abroad to have a hip replacement in another public hospital?

Do I need any kind of authorisation before I travel to another EU country for a hip replacement? Can you tell me how I go about requesting this authorisation (which institution should I contact, what documentation do I need, how long does it take, etc.)?

Will I be reimbursed for the costs involved if I get a hip replacement abroad? How much can I expect to be reimbursed?

How does payment work, do I have to pay for the costs myself and then be reimbursed? What about the costs associated with travelling there, are they reimbursed at all? How and where do I apply for reimbursement? Would you assist me in putting together my paperwork?

As I don’t know anyone else who has done this, I would really appreciate it if you could tell me if there is anything else I need to know about seeking this kind of treatment abroad? Is a referral needed?

What if something goes wrong – who would I get in touch with and how?

Will my treatment be followed up by the health services when I return to [Country X]?

I look forward to hearing from you – great to know you are there to answer my questions!

Best,

Box E.3 Email template Scenario 3

Subject: Cataract surgery abroad

Dear Sir/Madam,

I am from [Germany or Belgium], but a friend of mine told me that it is possible to travel to another EU country for health care. I am retired and have been on a pension for the last 7 years. Recently I am having trouble with my eyesight and when I visited my doctor, he said that I will need to have cataract surgery. My friend told me she knows of people who have gone to your country, as there are private surgeons that can do this much quicker than if I am on the waiting list here. I was wondering whether you can give more detailed information about this option.

Is my friend correct that I have the right to get this treatment in your country? Does it apply if I opt to have this surgery carried out by a private surgeon? I read something about some things needing to have authorisation, do I need authorisation for this?

Do I have to pay upfront for the surgery? What about refunding the costs-, will I be refunded? What will I be refunded for will it cover transport and accommodation?

Are you able to recommend a good private surgeon who performs cataract surgery? Or a good private hospital?

Do I need to show any special document to be accepted as a patient? Do I need a referral?

---

[10] Belgium, Germany, Greece, Spain, France, Italy, Luxembourg, Austria or Sweden.

If I do have this surgery in your country and something goes wrong, what do I have to do?

Finally, I assume that in order to get reimbursed I will have to provide invoices of the treatment I received. But what should I do if the invoices are written in a language I do not understand? Will there be assistance in translating the invoices?

Are there other considerations or information that you can give me?

I would really appreciate if you could help me find out more about this possibility.

Kind regards,

Box E.4 Email template Scenario 4

Subject: Orthopaedic consultation for my daughter

Dear Sir/Madam,

I am interested in the possibility of travelling to your country. My daughter was born with a clubfoot. We are from [Bulgaria or Romania] but I am interested in having a consultation with an orthopaedic surgeon in your country to seek another opinion about what treatment would help her. We have heard from other parents that early treatment is the most effective so we hope to find the right care for her whilst she is still young.

Do I have the right to travel with my daughter to your country to have an orthopaedic consultation? Is there any kind of authorisation that we would need?

What about the costs involved, what are my rights to be reimbursed? Which costs will I be paid back? Do I have to pay the costs upfront?

I would like to know what quality and safety standards there are in your country.

Due to my daughter’s disability, she has some difficulties walking. Can you tell me about the accessibility of hospitals?

If she then gets treatment in your country but something goes wrong, what do we do? What are our rights?

What documentation would we need for the hospitals in your country? Is a referral needed?

What else do we need to know in this case? Would you be able to recommend a specialist?

I’d be really grateful for any information and guidance you can provide

Are there other considerations or information that you can give me?

I would really appreciate if you could help me find out more about this possibility.

Kind regards,

ANNEX F – CONTACT INFORMATION NCPS (WP3)

AUSTRIA
Gesundheit Österreich GmbH
Website:
https://www.gesundheit.gv.at/Portal.Node/ghp/public/content/kontaktstellepatientenmobilitaet.html
Email: patientenmobilitaet@goeg.at
Telephone number: +43 (0)1 71100-0

BELGIUM
Soins de santé transfrontaliers
Website: www.crossborderhealthcare.be
Email: information@crossborderhealthcare.be
Telephone number: +32 (0)22902844

BULGARIA
National Health Insurance Fund Website: www.nhif.bg
Email: crossbordercare@nhif.bg
Telephone number: +359 2 965 9116

CROATIA
Croatian Health Insurance Fund
Website: www.hzzo.hr
Email address: ncp-croatia@hzzo.hr
Telephone number: + 385 1 644 90 90

CYPRUS
Ministry of Health
Website: www.moh.gov.cy/cbh
Email: ncpcrossborderhealthcare@moh.gov.cy
Telephone number: +357 22 605 407

CZECH REPUBLIC
Health Insurance Bureau
Website: www.kancelarzp.cz
Email: info@kancelarzp.cz
Telephone number: +420 236 033 411

DENMARK
Danish Patient Safety Authority
Website: http://stps.dk/da/borgere/internationalsygesikring/nationaltkontaktpunktforbehandling-i-eueoes
Email: IS-kontor@patientombuddet.dk
Telephone number: +4572286600

ESTONIA
Estonian Health Insurance Fund
Website: www.haigekassa.ee/kontaktpunkt
Email: info@haigekassa.ee
Telephone number: +372 669 6630

FINLAND
Kela
Website: www.hoitopaikanvalinta.fi
Email: yhteyspiste@kela.fi

FRANCE
Centre des Liaisons Européennes et Internationales de Sécurité Sociale (CLEISS)
Website: http://www.cleiss.fr/presentation/pcn.html
Email: soinstransfrontaliers@cleiss.fr
General telephone number: +33 1 45 26 33 41 (Monday, Wednesday, Friday: 9.00 – 12.30; Tuesday, Thursday: 14.00 – 17.00)

GERMANY
Deutsche Verbindungsstelle Krankenversicherung - Ausland (DVKA)
Website: www.eu-patienten.de
Email: info@eu-patienten.de
Telephone number: +49 228 9530-802/800 //+492289529

GREECE
National organization for health care services, provision, division of international affairs, National Contact Points GR Department Website: www.eopyy.gov.gr
Email: ncp_gr@eopyy.gov.gr
For Greek citizens seeking healthcare in the EU:
Telephone number: 210 8110935, 2108110936
For EU citizens intending to use Greek healthcare:
Telephone number: +30 2108110916, +30 2108110918, +30 2108110925, +30 2108110919

HUNGARY
Országos Betegjogi, Ellátottjogi, Gyermekjogi és Dokumentációs Központ
National Center for Patients' Rights and Documentation
For EU citizens that intend to use Hungarian healthcare:
Website: http://www.patientsrights.hu/
Email: info@patientsrights.hu

Telephone number: +36 20 999 0025
For Hungarian citizens seeking healthcare in EU:
Website: http://www.eubetegjog.hu/
Email: info@eubetegjog.hu
Telephone number: 06-80-620-600

IRELAND
Cross-Border Healthcare Directive Department
Website: http://hse.ie/eng/services/list/1/schemes/cbd/CBD.html
Email: Crossborderdirective@hse.ie
Telephone number: +353 (0)56 778 4546/4547/4556

ITALY
Ministry of Health, Directorate-General for health planning
Website: http://www.salute.gov.it/portale/temi/p2_4.jsp?lingua=english&area=healthcareUE
Contact form: http://www.salute.gov.it/portale/temi/p_sendMailNCP_ENG.jsp
No telephone number

LATVIA
National Health Service
Website: www.vmnvd.gov.lv
Email: nvd@vmnvd.gov.lv
Telephone number: +37167045005 Working days: 8:30 - 17:00 Lunch break: 12:30 - 13:00

LITHUANIA
State Health Care Accreditation Agency under the Ministry of Health
Website for NCP where patients could find the information in one place: www.lncp.lt
For EU citizens intending to use Lithuanian healthcare
Website: http://www.vaspvt.gov.lt/en
Email: contact.point@vaspvt.gov.lt
Telephone number: +370 5 261 5177 (open Monday – Thursday 8.00 – 12.00 and 12.45 – 17.00, Friday 8.00 – 12.00 and 12.45 – 15.45)
For Lithuanian insured persons seeking healthcare in the EU
National Health Insurance Fund under the Ministry of Health
Website: www.vlk.lt/vlk/en/
Email: vlk@vlk.lt
Telephone number: +37052364100 (open Monday – Thursday 8.00 – 12.00 and 12.45 – 17.00, Friday 8.00 – 12.00 and 12.45 – 15.45)

LUXEMBOURG
Service national d'information et de médiation santé
For EU citizens intending to use Luxemburgish healthcare:
Website: www.mediateursante.lu
Email: info@mediateursante.lu
Telephone number: +352 24 77 55 15 (open Monday – Tuesday 9.00 – 13.00, Wednesday 13.00 – 17.00, Thursday – Friday 9.00 – 13.00)
Ministry of Social Security (Caisse nationale de santé)
For Luxemburgish insured persons seeking healthcare in the EU:
Website: www.cns.lu
Email: cns@secu.lu
Telephone number: +352 27 57 - 1

MALTA
Ministry for Health
Website: http://health.gov.mt/en/cbhc/Pages/Cross-Border.aspx
Email: crossborderhealth@gov.mt
Telephone number: +356 22992381

NETHERLANDS
Netherlands NCP Cross-border Healthcare
Website: www.cbhc.nl
Contact form: www.cbhc.nl/nl-nl/contact
No telephone number

POLAND
National Health Fund
Website: http://www.kpk.nfz.gov.pl/en/
Email: ca17@nfz.gov.pl
Telephone number: +48 71 79 79 180

PORTUGAL
The Central Administration of the Health System
Website: http://diretiva.min-saude.pt/
Email: diretiva.pcn@acss.min-saude.pt
General telephone number: +351 21 792 58 00

ROMANIA
National Health Insurance House
Website: www.cnas-pnc.ro
E-mail: pnc@casan.ro
Telephone number: +40 (0)372 309 135

SLOVAKIA
Healthcare Surveillance Authority

Website: www.udzs-sk.sk
Email: web@udzs-sk.sk
General telephone number: +421-2-208 56 226

SLOVENIA
Health Insurance Institute of Slovenia (HIIS)
Website: http://www.nkt-z.si/wps/portal/nktz/home
Email: kontakt@nkt-z.si
Telephone number: +386 (0)1 30 77 222

SPAIN
Ministry of Health, Social Services and Equity
Website: http://www.msssi.gob.es/pnc/home.htm
Email: oiac@msssi.es
Telephone number: 901 400 100; +34 91 596 10 89; +34 91 596 10 90 (open June 16 to September 15 Monday to Friday 8.00 – 15.00, Saturday 9.00 – 14.00; winter: Monday to Frida 9.00 – 17.30, Saturday 9.00 – 14.00)

SWEDEN
For Swedish insured persons seeking healthcare in the EU:
Försäkringskassan
Website: www.forsakringskassan.se
Email: kundcenter@forsakringskassan.se; huvudkontoret@forsakringskassan.se
Telephone number: 771-524 524
For EU citizens intending to use Swedish healthcare:
Socialstyrelsen
Website: www.socialstyrelsen.se
Email: socialstyrelsen@socialstyrelsen.se
Telephone number: +46(0)75-247 30 00

UNITED KINGDOM
NHS *England*
Website: http://www.nhs.uk/NHSEngland/Healthcareabroad/Pages/Healthcareabroad.aspx
E-mail: england.contactus@nhs.net
Telephone number: +44 300 311 22 33
NHS 24 *Scotland*
Website: www.nhsinform.co.uk/rights/europe
Email: nhs.inform@nhs24.scot.nhs.uk
Telephone number: 0800 22 44 88
NHS Direct *Wales*
Website: www.nhsdirect.wales.nhs.uk/travelhealth/NCPs/
Email: NCPWales.amb@wales.nhs.uk
Telephone number: 0845 46 47
Health and Social Care Board HSC *Northern Ireland*
Website: www.hscboard.hscni.net/travelfortreatment/
Email: NationalContactPoint@hscni.net
Telephone number: +44(0)28 9536 3152
Gibraltar Health Authority
Website: www.gha.gi/
Email: infoGCHCP@gha.gi
Telephone number: +350 2000 7444

NORWAY
HELFO (The Norwegian Health Economics Administration)
Website: https://helsenorge.no/norwegian-national-contact-point-for-healthcare1
Email: servicesenteret@helfo.no
For Norwegians seeking information:
Telephone number: 800 43 573 (open from 8.00 – 15.30)
For callers outside Norway:
Telephone number: +47 23 32 70 30 (open from 8.00 – 15.30)

ANNEX G – ASSESSMENT FORMS MYSTERY SHOPPING (WP3)

Mystery Shopping – Assessment Form				
Mystery Shopper name			Date of email sent	
Country			Date of response email received	
Channels used	Telephone ☐	Email ☐	Attempts to call made	
Email address contacted			Date and time of final telephone call	
Telephone number contacted		No telephone number provided ☐	Duration of telephone call	

Scenario 1 – Reconstructive surgery (outbound patient)				
1	Were you able to enter into contact with the NCP?		Yes ☐	No ☐
2	Was the fact that there are two legal instruments which may apply (Regulation 883/2004 and Directive 2011/24/EU) explained?		Yes ☐	No ☐
	If yes, please provide the answer:			
3	Was it explained if the patient is entitled to receive hospital treatment domestically?		Yes ☐	No ☐
	If yes, please provide the answer:			
4	Was information provided about the availability of the necessary treatment domestically?		Yes ☐	No ☐
	If yes, please provide the answer:			
5	Was information provided about the typical waiting time for this type of surgery domestically?		Yes ☐	No ☐
	If yes, please provide the answer:			
6	Was it explained if the patient is entitled to receive *private* health care in another Member State?		Yes ☐	No ☐
	If yes, please provide the answer:			
7	Was it explained if the patient needs prior authorisation?		Yes ☐	No ☐
	If yes, please provide the answer:			
8	Was it explained which institution is competent to grant prior authorisation?		Yes ☐	No ☐
	If yes, please provide the answer:			
9	Did the NCP explain what documentation is needed?		Yes ☐	No ☐
	If yes, please provide the answer:			
10	Was it explained what the expected time period for requesting prior authorisation will be?		Yes ☐	No ☐
	If yes, please provide the answer:			
11	Was information about the right to be reimbursed provided?		Yes ☐	No ☐
	If yes, please provide the answer:			
12	Was information about the amount that will be reimbursed for the specific treatment provided?		Yes ☐	No ☐
	If yes, explain further:			
13	Was it explained which institution is responsible for reimbursement?		Yes ☐	No ☐
	If yes, please provide the answer:			
14	Was information provided about the payment procedure for the treatment?		Yes ☐	No ☐
	If yes, please provide the answer:			
15	Was information provided about the procedures of appeal and redress?		Yes ☐	No ☐
	If yes, please provide the answer:			
16	Was it explained whether the patient should pay upfront?		Yes ☐	No ☐
	If yes, please provide the answer:			
17	Was it explained if extra costs such as transportation or accommodation costs will be reimbursed?		Yes ☐	No ☐

	If yes, please provide the answer:		
18	Was it explained which documents need to be provided for reimbursement?	Yes ☐	No ☐
	If yes, please provide the answer:		
19	Did the NCP offer assistance in putting together the paperwork?	Yes ☐	No ☐
	Please explain further:		
20	Was it explained if a referral is needed?	Yes ☐	No ☐
	If yes, please provide the answer:		
21	Was information provided about accessing the patients' medical records?	Yes ☐	No ☐
	If yes, please provide the answer:		
22	Was information provided on the costs of accessing medical records?	Yes ☐	No ☐
	If yes, please provide the costs:		
23	Was information provided about where the patients will receive follow-up care?	Yes ☐	No ☐
	If yes, please provide the answer:		
24	Did the NCP provide information about receiving treatment abroad or patient feedback in the form of reports, flyers, video, infographics, etc?	Yes ☐	No ☐
	If yes, please explain further and provide materials shared by the NCP:		
25	Was a reference made to another contact or website? (Including a different NCP)	Yes ☐	No ☐
	If yes, please provide the answer:		
26	Did the NCP provide any additional information?	Yes ☐	No ☐
	If yes, please provide the information:		

Mystery Shopping – Assessment Form				
Mystery Shopper name			Date of email sent	
Country			Date of response email received	
Channels used	Telephone ☐	Email ☐	Attempts to call made	
Email address contacted			Date and time of final telephone call	
Telephone number contacted		No telephone number provided ☐	Duration of telephone call	

Scenario 2 – Hip replacement for a pensioner (outbound patient)

1	Where you able to enter into contact with the NCP?	Yes ☐	No ☐
2	Was the fact that there are two legal instruments which may apply (Regulation 883/2004 and Directive 2011/24/EU) explained?	Yes ☐	No ☐
	If yes, please provide the answer:		
3	Did the NCP indicate that they are not competent to grant authorisation or to pay the costs?	Yes ☐	No ☐
	If yes, please provide the answer:		
4	Did the NCP refer the patient to the NCP of another Member State?	Yes ☐	No ☐
	If yes, please provide the answer:		
5	Was it explained if the patient is entitled to receive *public* health care in another Member State?	Yes ☐	No ☐
	If yes, please provide the answer:		
6	Was it explained if the patient needs prior authorisation?	Yes ☐	No ☐
	If yes, please provide the answer:		
7	Was it explained which institution is competent to grant prior authorisation?	Yes ☐	No ☐
	If yes, please provide the answer:		
8	Did the NCP explain what documentation is needed?	Yes ☐	No ☐
	If yes, please provide the answer:		

9	Was it explained what the expected time period for requesting prior authorisation will be?	Yes ☐	No ☐
	If yes, please provide the answer:		
10	Was information about the right to be reimbursed provided?	Yes ☐	No ☐
	If yes, please provide the answer:		
11	Was information about the amount that will be reimbursed for the specific treatment provided?	Yes ☐	No ☐
	If yes, explain further:		
12	Was information provided about the payment procedure for the treatment?	Yes ☐	No ☐
	If yes, please provide the answer:		
13	Was information provided about the procedures of appeal and redress?	Yes ☐	No ☐
	If yes, please provide the answer:		
14	Was it explained if the treatment needs to be paid upfront?	Yes ☐	No ☐
	If yes, please provide the answer		
15	Was it explained if extra costs such as transportation or accommodation costs will be reimbursed?	Yes ☐	No ☐
	If yes, please provide the answer:		
16	Was it explained which institution is responsible for reimbursement?	Yes ☐	No ☐
	If yes, please provide the answer:		
17	Was it explained which documents need to be provided for reimbursement?	Yes ☐	No ☐
	If yes, please provide the answer:		
18	Did the NCP offer assistance in putting together the paperwork?	Yes ☐	No ☐
	Please explain further:		
19	Was it explained is a referral was needed?	Yes ☐	No ☐
	If yes, please provide the answer		
20	Was information provided about accessing the patients' medical records?	Yes ☐	No ☐
	If yes, please provide the answer:		
21	Was information provided about where the patients will receive follow-up care?	Yes ☐	No ☐
	If yes, please provide the answer		
22	Was a reference made to another contact or website?	Yes ☐	No ☐
	If yes, please provide the answer:		
23	Did the NCP provide any additional information?	Yes ☐	No ☐
	If yes, please provide the answer:		

Mystery Shopping – Assessment Form				
Mystery Shopper name			Date of email sent	
Country			Date of response email received	
Channels used	Telephone ☐	Email ☐	Attempts to call made	
Email address contacted			Date and time of final telephone call	
Telephone number contacted		No telephone number provided ☐	Duration of telephone call	

Scenario 3 – Cataract surgery for a pensioner (inbound patient)

1	Were you able to enter into contact with the NCP?	Yes ☐	No ☐
2	Was information about the right to cross-border treatment given?	Yes ☐	No ☐
	If yes, please provide the answer:		
3	Was information provided about the right to have the surgery carried out by a *private* surgeon?	Yes ☐	No ☐
	If yes, please provide the answer:		
4	Was it explained if the patient needs prior authorisation?	Yes ☐	No ☐
	If yes, please provide the answer:		

5	Was information about the right to be reimbursed provided?	Yes ☐	No ☐
	If yes, please provide the answer:		
6	Was information about the amount that will be reimbursed for the specific treatment provided?	Yes ☐	No ☐
	If yes, explain further:		
7	Was information provided about the payment procedure for the treatment?	Yes ☐	No ☐
	If yes, please provide the answer:		
8	Was information provided about the procedures of appeal and redress?	Yes ☐	No ☐
	If yes, please provide the answer:		
9	Was it explained if the treatment needs to be paid upfront?	Yes ☐	No ☐
	If yes, please provide the answer		
10	Was it explained if extra costs such as transportation or accommodation costs will be reimbursed?	Yes ☐	No ☐
	If yes, please provide the answer:		
11	Was it explained which institution is responsible for reimbursement?	Yes ☐	No ☐
	If yes, please provide the answer:		
12	Was it explained which documents need to be provided for reimbursement?	Yes ☐	No ☐
	If yes, please provide the answer:		
13	Was information provided on health care providers?	Yes ☐	No ☐
	If yes, please provide the answer:		
14	Was information provided about quality and safety standards?	Yes ☐	No ☐
	If yes, please provide the answer:		
15	Was information on documentation provided?	Yes ☐	No ☐
	If yes, please provide the answer:		
16	Was information provided about accessibility of hospitals for people with disabilities?	Yes ☐	No ☐
	If yes, please provide the answer:		
17	Was information about the need for a referral provided?	Yes ☐	No ☐
	If yes, please provide the answer:		
18	Was information provided about complaint procedures and mechanisms for seeking remedies?	Yes ☐	No ☐
	If yes, please provide the answer:		
19	Was information provided on the legal and administrative options to settle disputes?	Yes ☐	No ☐
	If yes, please provide the answer:		
20	Was information provided about the transfer of medical records?	Yes ☐	No ☐
	If yes, please provide the answer:		
21	Was information provided about what to do if invoices are in a foreign language?	Yes ☐	No ☐
	If yes, please provide the answer		
22	Did the NCP offer assistance to translate the invoices? Or did the NCP provide information about translating documentation?	Yes ☐	No ☐
	If yes, please provide the answer		
23	Was a reference made to another contact or website?	Yes ☐	No ☐
	If yes, please provide the answer:		
24	Did the NCP provide any additional information?	Yes ☐	No ☐
	If yes, please provide the answer:		

Mystery Shopping – Assessment Form				
Mystery Shopper name			Date of email sent	
Country			Date of response email received	
Channels used	Telephone ☐	Email ☐	Attempts to call made	
Email address contacted			Date and time of final telephone call	
Telephone number contacted		No telephone number provided ☐	Duration of telephone call	

Scenario 4 – Orthopaedic consultation for a disabled patient (inbound patient)			
1	Were you able to enter into contact with the NCP?	Yes ☐	No ☐
2	Was it explained if the patient is entitled to receive health care in another Member State?	Yes ☐	No ☐
	If yes, please provide the answer:		
3	Was it explained if the patient needs prior authorisation?	Yes ☐	No ☐
	If yes, please provide the answer:		
4	Was information about the right to be reimbursed provided?	Yes ☐	No ☐
	If yes, please provide the answer:		
5	Was information about the amount that will be reimbursed for the specific treatment provided?	Yes ☐	No ☐
	If yes, explain further:		
6	Was information provided about the payment procedure for the treatment?	Yes ☐	No ☐
	If yes, please provide the answer:		
7	Was information provided about the procedures of appeal and redress?	Yes ☐	No ☐
	If yes, please provide the answer:		
8	Was it explained if the treatment needs to be paid upfront?	Yes ☐	No ☐
	If yes, please provide the answer		
9	Was it explained if extra costs such as transportation or accommodation costs will be reimbursed?	Yes ☐	No ☐
	If yes, please provide the answer:		
10	Was it explained which institution is responsible for reimbursement?	Yes ☐	No ☐
	If yes, please provide the answer:		
11	Was it explained which documents need to be provided for reimbursement?	Yes ☐	No ☐
	If yes, please provide the answer:		
12	Was information provided about quality and safety standards?	Yes ☐	No ☐
	If yes, please provide the answer:		
13	Was information provided on health care providers?	Yes ☐	No ☐
	If yes, please provide the answer:		
14	Was information provided about accessibility of hospitals for people with disabilities?	Yes ☐	No ☐
	If yes, please provide the answer:		
15	Was information provided about complaint procedures and mechanisms for seeking remedies?	Yes ☐	No ☐
	If yes, please provide the answer:		
16	Was information provided on the legal and administrative options to settle disputes?	Yes ☐	No ☐
	If yes, please provide the answer:		
17	Was information provided about the transfer of medical records?	Yes ☐	No ☐
	If yes, please provide the answer:		
18	Was information provided about the need for a referral?	Yes ☐	No ☐
	If yes, please provide the answer		
19	Was a reference made to another contact or website?	Yes ☐	No ☐

	If yes, please provide the answer:			
20	Did the NCP provide any additional information?		Yes ☐	No ☐
	If yes, please provide the answer:			

ANNEX H – DETAILED DATA (WP3)

This annex provides additional detailed data harvested from the pseudo-patient investigations.

Reachability of the NCPs

The table below provides a detailed overview of the channels used by the pseudo-patients and whether the NCPs were reached successfully through these channels. In the analysis reachability stars were assigned according to the following guidelines: when the pseudo-patient made contact by email/phone and was able to make inquiries four stars were assigned; 3 stars were assigned when contact was made by email/phone after being forwarded or having to resend the email after which inquiries were made; when the pseudo-patient was able to make contact by email/phone but no inquiries addressed two stars were assigned; a single star was assigned when no contact by email/phone was made and no inquiries were addressed.

For Scenario 1, 2 and 3 one NCP was not contacted by phone as sufficient information was provided by email. Similarly, for Scenario 4, two other NCPs were not contacted by phone due to this reason. A total of three NCPs did not provide a telephone number for inquiries.

In terms of reachability there are some variations between NCPs for several reasons. NCPs may provide a reply later than the cut-off point of seven weeks, others were not reachable due to language barriers, and yet others were difficult to reach due to being forwarded or the need to resend the enquiry. Others requested the provision of additional or personal information.

Some NCPs provided information but there was a delay in delivery. One NCP sent a response to scenario 3 after five weeks. Another NCP sent a response to Scenario 4 after six weeks, for Scenario 3 it was sent after nine weeks and this response was not included in the analysis. Yet another NCP sent the response after five weeks for Scenario 1 and 4. It was communicated by the NCP that they legally have 30 days to respond to an email enquiry. In addition, one NCP sent a reply to the email enquiry up to 15 weeks later; these were also excluded from the analysis.

In scenario 3, one NCP was not reached due to language barriers of the call menu. Language barriers were also faced in two other MSs for the inbound scenarios.

In one particular case the pseudo-patient was forwarded to another body, in both scenario 1 and scenario 3.

One NCP could not provide any additional information for the outbound scenarios as personal information was required. In one MS outbound patients were requested to provide a referral from a doctor.

ANNEX I - ANALYSIS OF OTHER INFORMATION CENTERS (WP4)

This annex expands a preliminary comparison of the present cooperation between NCPs with other information centres and networks. This comparison aims to identify the possibilities to evolve to a more uniform practice and effective collaboration between NCPs. The idea behind it is to provide realistic pathways to improve the effectiveness of NCP collaboration, thus achieving a more consistent level of NCP service, and this at little extra cost, drawing on intelligence available in other policy fields. Possible tools towards these objectives are:

- Measuring instruments, such as guidelines, guiding principles, indicators;
- Support and information materials (e.g. FAQ, checklists, manuals...);
- European web portal;
- Benchmarking and monitoring.

Background - Present Collaboration

The Cross-border healthcare Directive 2011/24/EU prescribes a twofold way of cooperation. First NCPs should consult with other stakeholders in order to fulfil their duty to inform patients, namely with healthcare insurers, healthcare providers and patient organisations.[11] Second, NCPs should cooperate closely with each other and with the Commission.[12]

The Directive does not state how such cooperation amongst NCPs themselves must be established. However, it provides a framework for cooperation beyond NCPs in other areas such as European Reference Networks, e-health and health technology assessment.[13] Cooperation between NCPs and with the Commission can be seen in the light of new governances modes within the EU, which may according to Sable and Zeitlin all be reduced to the traditional underlining architecture of decision making in the EU.[14] The latter consisting of four elements:

- framework goals and measures for determining their achievements are established by joint action of the MSs and EU institutions;
- lower-level units such as national authorities are free in choice of means to achieve these goals;
- in return for this autonomy, they must report regularly on their performance and participate in peer review in which their results are compared with those pursuing other means to the same general ends;
- framework goals, performance measures, and decision-making procedures themselves are periodically revised by the actors.[15]

An example of such a new form of governance is the Open Method of Coordination (OMC). The OMC does not result in EU legislation, but is a method of soft governance which aims to spread best practice and achieve convergence towards EU goals in those policy areas which fall under the partial or full competence of MSs.[16] The OMC is principally based on:

- jointly identifying and defining objectives to be achieved;
- jointly established measuring instruments (statistics, indicators, guidelines);
- benchmarking, i.e. comparison of EU countries' performance and the exchange of best practices, peer review (monitored by the Commission).[17]

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[11] Art. 6(1) Directive 2011/24/EU.

[12] Art. 6(2) Directive 2011/24/EU.

[13] Chapter IV Directive 2011/24/EU.

[14] F. Sabel, J. Zeitlin, Learning from Difference: The New Architecture or Experimentalist vernance in the EU, *European Law Journal* 14(2008), 271-327.

[15] F. Sabel, J. Zeitlin, Learning from Difference: The New Architecture or Experimentalist Governance in the EU, *European Law Journal* 14(2008), 271-327.

[16] M. Prpic, The Open Method of Coordination: At a glance, EPRS, 2014, http://www.europarl.europa.eu/EPRS/EPRS-AaG-542142-Open-Method-of-Coordination-FINAL.pdf.

[17] See glossary of summaries on EUROPA, EUR-lex, http://eur-lex.europa.eu/summary/glossary/open_method_coordination.html.

Regardless of the existing opposition against the technique of OMC, some proponents advocate expanding the method to other areas such as health. The future will tell if cooperation under the Directive 2011/24/EU will lead to formalisation of OMC.[18]

The Evaluative Study showed that the general level of cooperation between different NCPs is relatively intense. A number of professional events, seminars and workshops, held after the adoption of Directive 2011/24/EU resulted in intense knowledge-sharing amongst the newly established NCPs.[19] Meetings with NCP coordinators, organised by the European Commission, are regularly held. The NCP survey showed that most NCPs evaluate cooperation with other NCPs as very positively.[20] However, it was also shown that cooperation between NCPs was mainly ad hoc. Enhancing cooperation and information exchange between NCPs was most often mentioned as possible improvements under Directive 2011/24/EU. A number of NCPs mentioned the usefulness of shared information platforms. Cooperation aiming to establish a more standardised way of NCP practice is still missing.[21] Such standardisation may, however, be a solution to redress current shortcomings in information provision to patients in cross-border healthcare.[22]

To map the possibilities for a more formal collaboration between NCPs, the current practice of some other information centres and their networks is analysed. These centres and networks differ greatly in organisation and working process but may all lead to some examples which may be used for NCP collaboration. Considering the starting point of new governance modes, the focus will be mainly on framework goals, performance measuring instruments and benchmarking.

Examples from other information centres and their networks

HORIZON 2020 NCPs

Horizon 2020 NCPs are national structures established and financed by governments of the EU MSs and the states associated to the Framework Programme Horizon 2020, which is the biggest EU Research and Innovation programme running from 2014 till 2020. The national system of NCPs is the main structure to provide guidance, practical information and assistance on all aspects of participation in Horizon 2020. NCPs ensure that the community is timely and adequately informed about open and upcoming calls. They support and assist researchers in the preparation and follow-up of their application.[23]

As the NCPs are national structures, appointed and financed at national level, the type and level of services offered may differ from country to country. In general, the following basic services are available in accordance with the NCP Guiding Principles agreed upon by all countries[24]:

- Guidance on choosing relevant Horizon 2020 topics and types of action;
- Advice on administrative procedures and contractual issues;
- Training and assistance on proposal writing;
- Distribution of documentation (forms, guidelines, manuals etc.);
- Assistance in partner search.

The national system of NCPs can vary from one country to another from highly centralised to decentralised networks, and involve a number of very different actors, from ministries to universities, research centres and special agencies to private consulting companies. However, all

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[18] T. Clemens, E. Cox, B. Van der Zanden et al., Activity Report. Implementation of National Contact Points for cross-border healthcare in EU MSs: a comparative analysis using websites and short interviews, Maastricht University, 2015.

[19] G. Zucca, A. De Negri, A. Berény, A. Kaszap, K.A. Stroetmann, P. Varnai, Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 36 and 60.

[20] See *infra*.

[21] G. Zucca, A. De Negri, A. Berény, A. Kaszap, K.A. Stroetmann, P. Varnai, Evaluative study on the cross-border healthcare Directive (2011/24/EU), 2015, 60.

[22] A. Santoro, A. Silenzi, W. Ricciardi, M. McKee, Obtaining health care in another European Union MS: how easy is it to find relevant information?, *Eur J of Public Health* (25)1 (2015) 29-31; G. Strban, G. Berki, D. Carrascosa, F. Van Overmeiren, Analytical Report 2016: Access to healthcare in cross-border situations, FreSsco, January 2017.

[23] http://ec.europa.eu/research/participants/portal/desktop/en/support/national_contact_points.html.

[24] Minimum Standards and Guiding Principles for setting up systems of National Contact Points (NCP systems) under HORIZON 2020, DG Research and Innovation, available at: http://ec.europa.eu/research/participants/data/support/20131125_NCP%20Minimum%20standards.pdf.

NCP systems have a common structure (National NCP coordinator, Legal and financial aspects NCP, SMEs NCP, Access to finance NCP, European Research Infrastructures NCP,…), as prescribed by the guiding principles.

The cooperation between HORIZON 2020 NCPs is thus founded in NCP Minimum Standards and Guiding Principles, agreed upon by all countries. These Guiding Principles start by defining the objectives to be achieved by all NCPs. Besides, a common set of key principles and minimum standards is established. Also, the core functions and core structure of an NCP are prescribed. Compliance with the guiding principles is monitored by the European Commission. The latter may "de-recognise" NCPs as a sanction in case of persisting non-compliance with the guiding principles. In case of "de-recognition" the NCP will be removed from the mailing lists and will no longer receive information directly from the Commission, including confidential information.

There is no H2020 NCP at EU level, nor an independent website. A web portal for participants is integrated in EUROPA, including assisting tools such as:

- H2020 Online Manual;
- FAQ;
- Specific contact details of each NCP (per function).[25]

The H2020 NCPs cooperate closely together in transnational joint networks, e.g. ACCESS4SMES[26], Idealist2018[27], Net4Society[28], HNN2.0[29], NCP Academy[30],... These international NCP networks all have a distinct web portal. Different tools are used in these networks to enhance cooperation between NCPs of different MSs. Examples are:

- information and training materials offered on the network's website, including webinars;[31]
- the organisation of advanced NCP training days and workshops;[32]
- online platform/Intranet for sharing questions among NCPs[33] or a joint Google group[34].

Besides, NCP coordinator meetings are regularly organised by the Commission. Also cooperation exists at regional level, e.g. in Belgium where there are 5 NCP organisations which work with a strict regional division according to the location of the seat of the organisation of the applicant, NCPs work together through the co-organisation of information sessions, strategic meetings, information sharing,...[35]

The NCP_WIDE.NET[36] is a transnational network of NCPs for Spreading Excellence and Widening Participation. In this network, a special focus is given to benchmarking and monitoring. The network is meant to help less experienced NCPs, which wish to draw on know-how accumulated in other countries and access resources in the network, through mentoring visits, a learning platform for trans-national activities of the Spreading Excellence and Widening Participation NCPs, and to create a network of NCPs exploiting the synergies of distributed knowledge, collective development and trainings.[37]

FreSsco Legal Experts

FreSsco (Free movement of workers and Social security coordination) is a network of independent legal experts in the fields of free movement of workers and social security coordination in the

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[25] http://ec.europa.eu/research/participants/portal/desktop/en/support/national_contact_points.html.

[26] Network of NCPs for Small Medium-sized Enterprises and Access to Risk Finance (SME and ARF).

[27] ICT NCP network.

[28] Network of NCPs for the Societal Challenge 6, "Europe in a changing world: inclusive, innovative and reflective societies".

[29] Network of NCPs for the Health, Demographic Change and Wellbeing Societal Challenge 1.

[30] Network of NCP Coordinators and Legal and Financial NCPs.

[31] E.g. website Net4Society.

[32] E.g. ACCESS4SMES.

[33] E.g. website Rich 2020 and NCP_WIDE.NET.

[34] Legal and Financial Google Group, NCP Academy.

[35] A. Van Hauwaert, NCP tools for daily work. Organisation at national level amongst multiple NCPs, http://www.ncpacademy.eu/wp-content/uploads/2017/06/20170530-31_NCPToolsForDailyWorkFlanders.pdf.

[36] Network of NCPs for Spreading Excellence and Widening Participation.

[37] See the website of NCP_Wide.Net, https://www.ncpwidenet.eu/project-wide-net/.

European Union. The network is funded by the European Commission and covers all 28 MSs, as well as Iceland, Liechtenstein, Norway and Switzerland. It consists of national legal experts on coordination and national legal experts on free movement, as well as analytical experts. The FreSsco network provides the European Commission with expertise via annual comparative reports on national legislation and ad hoc analytical support regarding specific themes. Besides, the network organises multiple seminars for stakeholders each year.[38]

The FreSsco network is operated by the University of Ghent, in partnership with the consultancy company Eftheia. It consists of a project management and coordination team[39], a team of independent national experts on coordination and on free movement of workers, a team of analytical experts, an advisory board and a communication web team.

A web portal for FreSsco is integrated in the EUROPA website. The annual reports and ad hoc analytical reports are published on the website. Besides, an integrated E-learning tool which consists of keywords and a list of Q&A per keyword is provided. Also, a list of all the members of the network is provided.[40]

The legal experts cooperate through LinkedIn: closed LinkedIn group *FreSsco Coordination* and closed LinkedIn group *FreSsco Free Movement of Workers.* Members are also informed through a bi-annual newsletter.

National SOLVIT centres

SOLVIT helps people who encounter difficulties in another country when public authorities do not apply EU legislation correctly; more specifically it tries to solve cases regarding breach of a citizen's right or a business' right by public authorities in another EU country.[41] SOLVIT is a service provided by the national administration in each EU MS, Iceland, Liechtenstein and Norway. SOLVIT centres are mostly organised within the Ministry of foreign or economic affairs. They work together via an online database, where they provide information on cases and on their practices.

Cases will be handled by two SOLVIT centres: the SOLVIT centre of the home country and the SOLVIT centre of the country where the problem occurred. The SOLVIT centre of the home country will submit the problem to the lead centre, which will try to find a solution with the public authority concerned. The target deadline is published on the SOLVIT website and counts 10 weeks, starting from acceptance of the case by the lead centre. SOLVIT is mainly an online service. An informative YouTube animation is provided on the SOLVIT portal on EUROPA to explain this procedure.

Minimum operational and quality standards are outlined in the 2013 SOLVIT governing recommendations established by the Commission.[42] In these recommendations the objective of SOLVIT is set out, as well as several guidelines for SOLVIT service, e.g. that the "SOLVIT service should be available by telephone or e-mail, and should provide a prompt reply to communications directed to them", that the deadline for handling cases must be limited to ten weeks, that refused cases must be based on appropriate justifications,... Besides, a set of guidelines prescribes how SOLVIT centres should be organised. Other chapters are for example the chapter on guidelines for regular quality checks and reporting. In May 2017 an Action plan on the Reinforcement of SOLVIT was published.[43] Reports on the NCP practice are published on the website.

There is no distinct website for SOLVIT at EU level. The SOLVIT website is integrated in EUROPA. A list of contact details of all national SOLVIT centres is provided. Although it is a national service, there is also a generalised contact form at EU level for submitting cases to SOLVIT. An inquiry or complaint can be submitted on one single portal, which can be experienced as a low-threshold procedure. On the SOLVIT portal also successful outcomes achieved by SOLVIT centres are published.

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[38] See the web portal of FreSsco on EUROPA, http://ec.europa.eu/social/main.jsp?langId=en&catId=1098.

[39] Consisting of a project director, project manager, scientific manager, project management assistant, editor and financial manager.

[40] See the web portal of FreSsco on EUROPA, http://ec.europa.eu/social/main.jsp?langId=en&catId=1098.

[41] See the web portal of SOLVIT on EUROPAhttp://ec.europa.eu/solvit/index_en.htm.

[42] Commission recommendation of 17 September 2013 on the principles governing SOLVIT, http://ec.europa.eu/solvit/_docs/2013/20130917_recommendation_solvit_en.pdf.

[43] http://ec.europa.eu/solvit/_docs/2017/com-2017-255_en.pdf.

NCP performance tracking data by indicator (first response time, preparation time, resolution time and resolution rate) are also published on the website.[44] Besides, analytical information on number of received cases, handling times, staffing level, etc. are provided for each MS.

On the SOLVIT portal on EUROPA there is also a page for website feedback and scoring "Help us improve our website". Visitors of the website are invited to answer 5 small yes/no questions regarding the user-friendliness and comprehensibility of the website. There is also the possibility to submit personal comments.

European Network of Information Centres in the European Region (ENIC)

The European Network of Information Centres in the European Region (ENIC) aims to implement the Lisbon Recognition Convention and aims, in general, to develop policy and practice for the recognition of qualifications.[45] The Council of Europe and UNESCO jointly provide the Secretariat for the ENIC Network. The ENIC Network cooperates closely with the NARIC Network (National Academic Recognition Information Centres in the European Union) of the European Union. The Network is made up of the national information centres of the Parties to Lisbon Recognition Convention. An ENIC is a body set up by the national authorities. While the organisation and specific competences of ENICs may vary, they will generally provide information on:

- the recognition of foreign diplomas, degrees and other qualifications;
- education systems in both foreign countries and the ENIC's own country;
- opportunities for studying abroad, including information on loans and scholarships, as well as advice on practical questions related to mobility and equivalence.[46]

There is one ENIC bureau at EU level, consisting of a president and 2 vice-presidents, elected for 2 years. The ENIC Bureau meets twice or three times a year. Representatives of national ENIC centres meet once a year, meanwhile ad hoc parties deal with specific topics. Working Parties prepare proposals for the annual network meeting. The network also plays an important role in the exchange of information between national centres.

In June 2004, the Joint ENIC-NARIC charter was adopted by the Committee of the Convention on the Recognition of Qualifications concerning Higher Education in the European Region.[47] The charter prescribes the tasks and activities of national ENIC and NARIC centres and their networks, including guidelines for their staff and technical equipment.

There is an independent website at EU level for both the ENIC network and the NARIC network. The website provides a country page with information for each MS, containing references to all relevant national actors and official information on e.g. the national information centres, national education bodies, system of education, university education,...

The website provides an e-manual (EAR manual)[48] which contains standards and guidelines on all aspects of the recognition of foreign qualifications and aims to provide the credential evaluators from the ENIC and NARIC networks with a practical tool to assist them in their daily recognition work.

Expert Reviewers for Orphanet

The Orphanet network consists of expert reviewers who annually contribute to updating the scientific information contained in the Orphanet database of rare diseases.[49] Expert reviewers are recognised each year. The experts are chosen after being identified through their publications and their activity. They are invited to examine a form containing scientific information related to given diseases that is pre-filled with information of the Orphanet database.

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[44] Action plan on the Reinforcement of SOLVIT: Bringing the benefits of the Single Market to citizens and businesses (Communication from the Commission), http://ec.europa.eu/internal_market/scoreboard/performance_by_governance_tool/solvit/index_en.htm.

[45] See the ENIC-NARIC website: http://www.enic-naric.net.

[46] See the ENIC-NARIC website: http://www.enic-naric.net/welcome-to-the-enic-naric-website.aspx.

[47] Joint ENIC-NARIC charter of activities and services, 2004, available at: https://rm.coe.int/16807462ca.

[48] http://ear.enic-naric.net/emanual/.

[49] Expert reviewers for Orphanet in 2016, Orphanet report series, available at: http://www.orpha.net/orphacom/cahiers/docs/GB/Expert_reviewers_2016.pdf.

The Orphanet network makes use of an independent website. On the website, access to the Orphanet database is made available. Besides, a vocabulary tool, Orphanet Rare Disease Ontology (ORDO) is provided which consists of a structured vocabulary for rare diseases derived from the Orphanet database, capturing relationships between diseases, genes and other relevant features, which will form a useful resource for the computational analysis of rare diseases. Also, Orphanet reports are regularly published and updated.

The cooperation between expert reviewers consists of a platform for experts. As mentioned, the network consists of an ad hoc composition. A list of the experts reviewers is published each year. The procedure is regulated in the Orphanet Standard Operating Procedures version 02.1, published in June 2016.[50]

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[50] Orphanet Standard Operation Procedures 02.1, June 2016, available at: http://www.orpha.net/orphacom/special/eproc_SOPs_V2.pdf.

Overview

	MEASURING INSTRUMENTS	SUPPORT AND INFORMATION MATERIALS	EUROPEAN WEB PORTAL	COOPERATION	REGULAR MEETINGS	BENCHMARKING
HORIZON 2020 NCPs	NCP Minimum Standards and Guiding Principles	• H2020 Manual; • FAQ.	Integrated in EUROPA: • Support and information materials; • Contact details NCPs (per function).	Several international joint networks	NCP coordinator meetings, organised by the EC to: • Discuss collaboration; • Share experiences; • Identify good practices; • Address problems.	Sharing experiences during meetings, best practices, trainings.
FreSsco	--	• E-learning tool.	Integrated in EUROPA: • Support and information material; • List of members.	Closed LinkedIn groups.	10 seminars with other stakeholders a year.	--
SOLVIT	2013 SOLVIT governing recommendations	• YouTube animation fragment; • General contact form; • Success stories.	Integrated in EUROPA: • Support and information materials; • List of contact details SOLVIT centres; • Analytical information.	SOLVIT database.	--	Analytical SOLVIT information; regular quality checks and reporting.
ENIC	ENIC-NARIC charter	• E-manual; • The ENIC-NARIC Networks: Reference Documents (e.g. legal framework and background; adopted documents)	Independent website: • Contact details and information per MS.	• Ad hoc parties; • Joint meetings.	Annual network meetings.	--
Orphanet	Orphanet Standard Operating Procedures version 02.1	• Orphanet database; • ORDO (Orphanet Rare Disease Ontology).	Independent website: • Support and information materials; • List of expert reviewers.	Orphanet database.	Expert platform.	--

Recommendation for NCPs for Cross-border healthcare

Five main recommendations may be formulated based on the results of the analysis:

1. Develop standardised measuring instruments, such as guiding principles and indicators;
2. Use support and information materials (e.g. manuals, FAQ, e-learning tool, webinar);
3. Collect analytical information on the NCP practice for monitoring and benchmarking;
4. Create an EU web portal for NCPs, including analytical information, website feedback, information on the healthcare system per MS;
5. Establish joint networks between NCPs.

ANNEX J – ONLINE SURVEY PATIENTS (WP4)

MS	Patient organisation	Website
Austria	Österreichische Krebshilfe (National coalition of cancer assocations)	www.krebshilfe.net
Belgium	Flemish patient platform (Flemish coalition of patient organisations)	www.vlaamspatientenplatform.be
On suggestion of the Flemish patient platform:	*Angelman Syndroom België*	www.angelmansyndroom.be
	Angioedema Belgium vzw	www.angioedema.be
	Bardet-Biedl Oudercontact	www.angelfire.com/co3/PEKICH
	Ectodermale dysplasie België/Nederland	www.vved.info
	Interstitiële Cystitis Patiëntenvereniging België	www.icpb.be
	Liga Myasthenia Gravis vzw	www.ligamg.be
	MSA-AMS vzw	www.msa-ams.be
	Prader-Willi Vlaanderen vzw	www.praderwillivlaanderen.be
	Ligue des Usagers des Services de Santé (French coalition of patient organisations)	www.luss.be
Bulgaria	NPO - National Patients' Organisation (National coalition of patient organisations)	www.npo.bg.
Croatia	KUZ - Coalition of Associations in Healthcare (National coalition of patient organisations)	www.kuz.hr
Cyprus	Pancyprian Federation of Patients Associations and Friends (National coalition of patient organisations)	www.cypatient.org
Czech Republic	Arcus onko centrum (Cancer patient organisation)	www.arcus-oc.org
	Česká asociace pro vzácná onemocnění (Czech Association for Rare Diseases)	www.vzacna-onemocneni.cz
Denmark	Danske Patienter/ Danish patients (Association of 81 patients associations in Denmark)	www.danskepatienter.dk
Estonia	EPIK - Estonian Chamber of Disabled People (National coalition of patient organisations)	www.epikoda.ee
Finland	Cancer society of Finland (Coalition of 12 regional cancer associations and six national patient organisations)	www.cancersociety.fi
France	l'Union nationale des associations agréées d'usagers du système de santé (période de transition le CISS) (National coalition of 72 patient organisations)	www.leciss.org

Contacted patient organisations

MS	Patient organisation	Website
Germany	BAG Selbsthilfe - Federal Association of Self-Help Organisations for people with disabilities and chronic diseases and their relatives (National coalition patient organisations)	www.bag-selbsthilfe.de
Greece	NCDP - National Confederation of Disabled People (National coalition patient organisations)	www.esaea.gr
Hungary	BEMOSZ - Hungarian Alliance of Patients' Organisations (National coalition of patient organisations)	www.bemosz.hu
Iceland	ÖBÍ - Organisation of Disabled in Iceland (National coalition of patient organisations)	www.obi.is
Ireland	Irish Cancer Society (National cancer organisation)	www.cancer.ie
	Irish patients' Association (National patient advocacy organisation)	www.irishpatients.ie
Italy	F.A.V.O. Federazione Italiana delle Associazioni di Volontariato in Oncologia (National coalition of cancer patient organisations)	www.favo.it
Latvia	SUSTENTO - The Latvian Umbrella Body for Disability Organization (National coalition patient organisations)	www.sustento.lv/?lang=en
Lithuania	LPOAT - Council of Representatives of Patients' organizations of Lithuania (National coalition patient organisations)	www.pacientutaryba.lt
Luxembourg	Patiente Vertriedung (National patient organisation that offers advice and information on administrative, technical, medical and care problems in the areas of health and social security)	www.patientevertriedung.lu
Malta	MHN - Malta Health Network (National coalition of patient organisations)	maltahealthnetwork.org
Netherlands	Patiëntenfederatie Nederland (National coalition of patient organisations)	www.patientenfederatie.nl
Norway	Kreft Foreningen (National cancer patient organisation)	www.kreftforeningen.no
	FF0 – Norwegian Federation of Organizations of Disabled people (National coalition of 82 patient organisations for people with disabilities and chronic diseases)	http://www.ffo.no
Poland	FPP - Federation of Polish Patients (National coalition of patient organisations)	www.federacjapp.pl
Portugal	Raríssimas (National organisation for rare diseases)	http://www.rarissimas.pt/index.php
Romania	COPAC - Coalition of Patients' Organizations with Chronic Diseases (National coalition of patient organisations)	www.copac.ro
	RONARD - Romanian National Alliance for Rare Diseases	www.apwromania.ro

Slovakia	AOPP - Association for the Protection of Patients' Rights (National coalition of patient organisations)	www.aopp.sk
Slovenia	Cancer Patients Association of Slovenia (National cancer patient organisation)	www.onkologija.org
Spain	FEP - Spanish Patients' Forum (National coalition of patient organisations)	www.forodepacientes.org
Sweden	HSO - Swedish Disability Federation (National coalition of patient organisations)	www.hso.se
United Kingdom	Patients Association (National patient organisation)	www.patients-association.org.uk
	National Voices (National coalition of patient organisations)	www.nationalvoices.org.uk
Additional patient organisations contacted on 10 November:		
	European Patients' Forum, EPF	www.eu-patient.eu
	International Federation for Spina Bifida and Hydrocephalus	www.ifglobal.org

Template online survey

Patients in Cross-border Healthcare Survey	
#	Question
1	How many times did you travel to another country (EU MS, Norway, Iceland or Liechtenstein) with the purpose of receiving medical treatment?
2	Did you receive cross-border healthcare from a public or private healthcare provider?
3	Did you receive cross-border care physically or through telemedicine?
4	Did you apply for authorisation of the cross-border treatment with your national healthcare institution?
5	Did you need authorisation from your national healthcare institution in order to receive your cross-border treatment?
6	What was the reason you travelled to another country to receive medical treatment or telemedicine?
7	Do you know about the existence of National Contact Points for Cross-border Healthcare?
8	Before travelling abroad for medical treatment or telemedicine, did you already know about your right to receive medical treatment in another EU country and being reimbursed for that treatment by your own health insurance institution?
9	By what means did you learn about your right on reimbursable cross-border healthcare?
10	Prior to filling out this survey, did you know that there are two ways to receive reimbursable healthcare in another country, more specifically on the basis of the European Directive 2011/24/EU on patient's rights in cross-border healthcare and on the basis of the Social Security Regulation (EC) No 883/2004?
11	By what means did you learn of the existence of National Contact Points for Cross-border Healthcare?
12	Did you have contact with a National Contact Point for Cross-border Healthcare during your process of medical treatment abroad?
13	With which National Contact Point for Cross-border Healthcare did you have contact during your process of medical treatment abroad?
14	Did you encounter difficulties in the transfer of medical documents between your healthcare providers at home and the healthcare provider in the MS of treatment?
15	Which institution did you contact or which webpage did you consult in order to obtain information with regard to the medical treatment or telemedicine abroad?
16	Which public website did you consulted in order to obtain information on the cross-border treatment or telemedicine?
17	Did you experience difficulties in finding information with regard to medical treatment or telemedicine abroad?
18	How did you experience the level of comprehension and clarity of the information provided with regard to the process of medical treatment or telemedicine abroad?
19	Did you experience any language difficulties in finding and receiving information on the country of treatment or telemedicine?
20	Did you search for information in English on the country of treatment?

Patients in Cross-border Healthcare Survey	
21	Was it easy to find information in English?
22	On which aspects of the process of cross-border treatment did you search for information?
23	On which aspects of the process of cross-border treatment did you experience difficulties finding or understanding information?
24	Please evaluate, when applicable, your experience with information gathering on the following topics: Prior authorisation, Reimbursement, Quality and safety, Healthcare providers abroad, Accessibility of hospitals for people with disabilities, Complaint and redress procedures, Transfer of medical records, Waiting times.
25	Did you receive reimbursement for your medical treatment or telemedicine abroad?
26	Please indicate what is applicable regarding the reimbursement for your medical treatment or telemedicine abroad: I received partial reimbursement for the cross-border treatment, I received full reimbursement for the cross-border treatment.
27	Please indicate what is applicable regarding the reimbursement for your medical treatment or telemedicine abroad: I received medical treatment free of charge at point of use, I only had to pay directly a small portion of the total amount of the medical treatment abroad myself, I paid the medical treatment upfront and received reimbursement from the healthcare insurer in the MS of treatment, I paid the medical treatment upfront and received reimbursement afterwards from my own healthcare insurer, "Other".
28	Did you experience any difficulties with regard to obtaining reimbursement for your cross-border treatment?
29	Please indicate what is applicable regarding your experience with regard to obtaining reimbursement for your cross-border treatment.
30	Were you satisfied with the quality of care you received abroad?
31	Did you search in advance for information on quality and safety of care in the country where you whished to receive treatment?
32	Please indicate what is applicable: It was easy to find information on quality and safety in the country of treatment, It was difficult to find any information on quality and safety in the country of treatment.
33	Are there specific problems in information provision you have encountered during your process of medical treatment or telemedicine abroad that you would like to share?
34	Are there specific aspects to information provision to patients in cross-border healthcare, which you believe should be enhanced?
35	Do you have any other remarks you would like to share?

ANNEX K - URLS OF THE NCP WEBSITES OF THE 28 MSS + NORWAY

Country	URL	Inbound / outbound	Nr. of websites
Austria	https://www.gesundheit.gv.at/service/patientenmobilitaet/kontaktstelle-patientenmobilitaet	no	1
Belgium	www.crossborderhealthcare.be	no	1
Bulgaria	www.nhif.bg	no	1
Croatia	www.hzzo.hr	no	1
Cyprus	www.moh.gov.cy/cbh	no	1
Czech Republic	www.kancelarzp.cz	no	1
Denmark	http://stps.dk/da/borgere/internationalsygesikring/nationaltkontaktpunktfor-behandling-i-eueoes	no	1
Estonia	www.haigekassa.ee/kontaktpunkt	no	1
Finland	www.hoitopaikanvalinta.fi	no	1
France	http://www.cleiss.fr/presentation/pcn.html	no	1
Germany	www.eu-patienten.de	no	1
Greece	www.eopyy.gov.gr	no	1
Hungary	http://www.patientsrights.hu/ (http://www.eubetegjog.hu/)	no	1
Ireland	http://hse.ie/eng/services/list/1/schemes/cbd/CBD.html	no	1
Italy	http://www.salute.gov.it/portale/temi/p2_4.jsp?lingua=english&area=healthcareUE	no	1
Latvia	www.vmnvd.gov.lv	no	1
Lithuania	www.lncp.lt (for information in one place) (http://www.vaspvt.gov.lt/en) (http://www.vlk.lt/vlk/en/)	no	1
Luxembourg	www.mediateursante.lu www.cns.lu	yes	2
Malta	http://health.gov.mt/en/cbhc/Pages/Cross-Border.aspx	no	1
Netherlands	http://www.cbhc.nl/en-us/	no	1
Norway	https://helsenorge.no/norwegian-national-contact-point-for-healthcare1	no	1
Poland	ca17@nfz.gov.pl	no	1
Portugal	diretiva.pcn@acss.min-saude.pt	no	1
Romania	www.cnas-pnc.ro	no	1
Slovakia	www.udzs-sk.sk http://www.nkm.sk/en_GB/web/guest/home	yes	2
Slovenia	http://www.nkt-z.si/wps/portal/nktz/home	no	1
Spain	http://www.msssi.gob.es/pnc/home.htm	no	1
Sweden	www.forsakringskassan.se www.socialstyrelsen.se	yes	2
United Kingdom	https://www.nhs.uk/NHSEngland/Healthcareabroad/Pages/Healthcareabroad.aspx (England) http://www.nhsinform.scot/ (Scotland) www.nhsdirect.wales.nhs.uk/travelhealth/NCPs/ (Wales) http://www.hscboard.hscni.net/travelfortreatment/ (Northern Ireland) http://www.gha.gi (Gibraltar)	no	5

ANNEX L – WORKSHOP PROCEEDINGS

On 8 March 2018, a workshop/meeting of National Contact Points (NCPs) for cross-border healthcare was held on European Commission premises in Brussels. Below a brief overview of the proceedings of this workshop is presented.

Welcome and Introductory remarks

The Commission welcomed all attendees, and the agenda was adopted. The Commission introduced the representative of the European Court of Auditors who attended the workshop exceptionally on this occasion. The forum was briefed on the ongoing performance audit on cross-border healthcare within the framework of Directive 2011/24/EU. The audit would focus on the functioning of NCPs, e-Health strategies and rare disease patient policies. It was explained that a number of Member States were selected for in-depth visits and these would be contacted by the Court of Auditors in due course.

Then, the Study on Cross-border Health services: Enhancing Information Provision to Patients was introduced. On behalf of the project team, the moderator introduced the team in charge of the study consisting of KU Leuven, GfK and Ecorys. Additionally, the aim and objective of the workshop were discussed, as well as the focus of the day: "feeding back and learning from each other". The objectives of the study were three-fold: (i) to identify the information needs of patients; (ii) to assess how the NCPs collect the information and provide it to patients; and (iii) to propose practical tools and guiding principles to improve the information provision by the NCPs.

Results of NCP Website Analysis (Work Package 2)

On behalf of the project team, Ecorys presented the preliminary results of Work Package 2: Website Analysis. One NCP (Ireland) gave an overview of developments in their Member State related to their approach to ensuring a good website for the National Contact Point function. The main issues that were touched upon include amongst others: difficulties in providing reimbursement information on the website, the requirement of the availability of information in both native and English language, and continuous improvement of the websites so that the end-user perspective can be enhanced.

Results of NCP Pseudo-Patient Investigation (Work Package 3)

On behalf of the project team, GfK presented the methodology and preliminary results of the pseudo-patient investigation conducted between August and October 2017. In a nutshell, 55% of NCPs responded to at least half of the questions in the email or telephone inquiries, on average. 24% of NCPs were able to respond to the majority of questions, on average. 10% of NCPs were not able to provide any information to the pseudo-patients.

With regards to the evaluation of the replies received, the project team informed that the assessment of the replies was built on a series of binary values indicating whether the answers were provided or not. They did not investigate whether the answers provided to the pseudo-patients by each NCP were right or wrong. GfK further confirmed that in some cases, pseudo-patients were told by the NCPs that they were not allowed or were unable to give a certain piece of information.

Issues that were touched upon by the NCPs were amongst others: case management by NCPs, legal restrictions of the NCPs and the use of Social Media to inform patients.

Draft Toolbox and Training Material including Guiding Principles (Work Package 4)

The KU Leuven representative presented the draft toolbox, draft training material and the eleven draft Guiding Principles for good NCP conduct. To facilitate the discussion, the NCPs were asked to express their opinions on each draft guiding principle via an interactive voting tool. The NCPs were able to vote (yes or no) on whether they agree with the overall principles and the preliminary underlying guidelines and indicators. The voting tool then showed the results on screen in a real-time setting.

In general, the draft guiding principles underpinning the guidelines were not as queried as the preliminary guidelines and indicators supporting them. In light of the detailed feedback received during and further to the workshop, KU Leuven proposed to revise the draft guidelines and indicators and resubmit them via written consultation in spring 2018 to the NCPs.

Looking Ahead: Interactive Session on Implementation of the Draft Toolbox and Next Steps

No NCP representative queried the intrinsic value of good NCP conduct and the added value of streamlining information provision in the interest of patients. None questioned the choice of the present methodology and its roll-out as a vehicle to map the current state of play on the ground.

NCPs were thus invited to share their views on the draft guidelines and toolbox with the consortium on the last mile before the study finalisation. It was requested to take into account, in the assessment of NCPs' functioning, national specificities and the diverse ways in which NCPs are organised.

Wrap-up of the day

The Commission and the project team thanked participants for their attendance and views and announced that the timeline for publication of the study on enhancing information provision to patients would be summer/ early autumn.

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